

# **The ‘Open Window’ Study**

**A mixed methods research design evaluating the psychological effect of ‘Open Window’ and exploring the experiences of people undergoing stem cell or bone marrow transplant for the treatment of haematological malignancies**

## **Preliminary Findings**

Thesis Submitted for PhD

By

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## **Declaration**

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## **Summary**

### **Background**

‘Open Window’ is a novel art intervention currently available in the National Bone Marrow Transplant Unit at St. James’ Hospital, Dublin where patients undergo stem cell or bone marrow transplantation for the treatment of haematological malignancies. It comprises a multimedia system that uses a combination of video projectors, audio speakers and bespoke software to make images (video with accompanying music and photography), produced by national and international artists, appear as a ‘virtual window’ on the wall of the patients’ room. Artists use mobile phone cameras to record images that are sent to the unit over the internet via mobile phone networks or if the patient wishes, a family member may take a mobile phone and submit images of familiar places or family in the same way. Patients access and manipulate the system using remote control.

Patients in the transplant unit receive treatment in single, en suite, air conditioned rooms with restrictions on room décor and visiting due to the high risk of infection. ‘Open Window’ is available in 8 rooms and was designed to improve patients’ experience of undergoing stem cell or bone marrow transplantation and possibly have a long term effect. The four main aims of ‘Open Window’ are to: provide a sense of connection with the outside world; provide a relaxing environment; provide an opportunity and environment conducive to self-reflection and extend current art practice in health care contexts. The purpose of this study was to test the null hypothesis that ‘Open Window’ has no effect on participants’ levels anxiety, depression and distress over time and explore how it may have influenced their experience of undergoing stem cell or bone marrow transplantation.

### **Study Design**

A randomised controlled trial design using mixed methods for data collection and analysis was regarded as the most appropriate for achieving the aims of this study. The use of both questionnaires and semi-structured interviews provides

subjective data on participants' experience of 'Open Window' and also allows any psychological effect to be measured over time. Ethical approval was given by hospital Research Ethics Committee. For the interim analysis presented in this study 29 patients undergoing autologous transplantation and 39 undergoing allogeneic transplantation (36 in the intervention group and 32 in the control group) consented to take part and were randomly allocated to room either with or without OW. The Hospital Anxiety and Depression Scale (Zigmond and Snaith 1983) and the Distress Thermometer (Roth et al. 1998) were used to measure any psychological effect. A 30-item survey questionnaire was designed to assess participant views and experiences of OW and a single-item 'Expectations' questionnaire was used to determine if OW affected participants' overall experience of having a stem cell or bone marrow transplant. Thirty patients from both the intervention and control group were interviewed also.

### **Findings**

Repeated measures ANOVA with between-subjects effects was used to measure differences in levels of anxiety, depression and distress over time. Results showed overall low levels of anxiety, depression and distress and that even though the intervention samples had slightly lower scores for all three outcomes than the control samples, the differences were not statistically significant regardless of age, gender or educational level. However, a statistically significant difference ( $p=.008$ ) is evident between the overall scores for the intervention and control samples in relation to their expectations of having a stem cell or bone marrow transplant with the intervention groups reporting a their experience better than expected. Given the randomised controlled design of this study, it is possible to attribute this difference to their experience of 'Open Window', however, as these results present interim findings only, they should be regarded with caution as a larger sample may elicit different results (Power calculations suggest that a sample of 400 is required). Qualitative data indicates that participants felt the value of 'Open Window' was in its ability to distract them from their immediate physical and psychological situation and connect them with the outside world.

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# **Chapter 1: Overview of the ‘Open Window’ Study**

## **1.1 Introduction**

This chapter provides an overview of the background to the ‘Open Window’ study and a detailed outline of each of the following six chapters in this thesis. It begins with an introduction to the development of the ‘Open Window’ project. This is followed by an outline of the relevant literature and theories and details on the aims and methods of the study. A summary of the findings, discussion, implications and recommendations are provided in the last section.

## **1.2 ‘Open Window’ Project**

Transplantation of haematopoietic stem cells is an established and growing treatment for haematological malignancies, particularly in the last ten years, with convincing results and reduced transplant-related mortality (Russell et al. 2004). It includes autologous and allogeneic transplants of stem cells from bone marrow or peripheral blood. The National Adult Bone Marrow Transplant Unit is located in the Denis Burkitt Unit, at St. James’ Hospital, Dublin.

In 2003, a prototype of ‘Open Window’ was installed in the Denis Burkitt Unit on a pilot basis. ‘Open Window’ is a novel art based intervention comprising a multimedia system that uses a combination of video projectors, audio speakers and bespoke software to make images (video with accompanying music and photography), produced by national and international artists, appear as a ‘virtual window’ on the wall of the patient’s room. Artists use mobile phone cameras to record images that are sent to the unit over the internet via mobile phone networks or, if the patient wishes, a family member may take a mobile phone and submit images of familiar places or family in the same way. Patients access and manipulate the system using remote control. The four main aims of ‘Open Window’ are as follows:

- To provide a sense of connection with the outside world;

- To provide a relaxing environment;
- To provide an opportunity and environment conducive to self-reflection
- To extend current art practice in health care contexts.

The primary reason that ‘Open Window’ was located in the Denis Burkitt Unit was that the director of the unit and professor of haematology, Professor Shaun McCann, had a personal interest in art and held the belief that art can help people psychologically by enhancing the environment and relieving boredom. This is particularly relevant to patients in this unit as the process of undergoing stem cell or bone marrow transplantation requires long periods of time in protective isolation in single rooms with restricted visiting, and children under 14 years of age are not permitted. The room décor is minimalist with a clinical effect due to the presence of medical equipment. However, it is important to point out that ‘Open Window’ was designed as an art project relevant to many health care contexts and is potentially helpful to any patient regardless of their illness.

Professor McCann’s interest in this issue led to the development of the prototype by the artist, Denis Roach, and resulted in the establishment of the ‘Open Window’ project team, which was headed by Professor McCann and included representatives from psycho-oncology services, nursing, medical physics department and the art world. The ‘Open Window’ prototype was installed initially in 2 rooms in the Denis Burkitt Unit in 2003. Following a decision to conduct a clinical trial to evaluate the psychological effect of ‘Open Window’, successful grant applications were made to the Irish Cancer Society and Vodafone Foundation Ireland. The Irish Cancer Society funding facilitated the employment of a research fellow and curator for the study and the Vodafone Foundation Ireland funding was for the further development and installation of an updated ‘Open Window’ system in 8 rooms in the Denis Burkitt Unit in July 2005 to enable commencement of this clinical trial.



### **1.3 Literature Review**

To provide background information on the theories underpinning the ‘Open Window’ study that was relevant and up-to-date, a comprehensive search of the literature was conducted. Electronic search of databases including Art Index, Cochrane Library, Google Scholar, Nature Journals, Proquest, PsychARTICLES, PsychINFO, Pubmed, Social Science Citation Index, Synergy and Wiley Interscience was conducted. Manual searches were also conducted of all relevant journals and related material held in the Trinity Libraries. References lists of all relevant articles were used to ensure that important literature was not omitted. Searches were confined to the past 25 years although some older relevant literature is included. Key words included life threatening illness, haematological malignancies, quality of life, randomised controlled trials, mixed methods research, art in health, design, and museum visitor research. The review was written in two parts in chapters 2 and 3.

Chapter 2 introduces the four key concepts underpinning this study; health care environments, living with a life threatening illness, art and design and art in health care. The historical belief in the healing powers of art and nature in health care versus the modern emphasis on functionality and efficiency of health care environments is discussed. A comprehensive review and critique of studies evaluating the effect of art in health highlight that not only is the research limited, but it also lacks rigor.

The idea of art in hospitals, as opposed to art in conjunction with design features, in hospitals considered as a potentially essential component of the psychological care of patients with a life threatening illness is presented in this chapter. Psychological theories explaining how art in health care contexts can help patients, particularly those with chronic or life threatening illness are discussed. These include The Social Cognitive Transition (SCT) Model of Adjustment (Brennan 2001) and Benson’s (1993) Theory of Aesthetic Absorption.

A review of the literature on quality of life studies in cancer patients revealed a large number that measured various determinants of quality of life. Chapter 3 explores the concept of quality of life in relation to cancer patients. Anxiety, depression and distress are regarded as the main emotional responses to a diagnosis of, and treatment for cancer and are frequently measured in quality of life studies using questionnaires such as the Hospital Anxiety and Depression Scale (HADS) and the Distress Thermometer (DT). Quality of life is generally classified as health related (HRQoL) or individualised (IQoL).

The studies reviewed in chapter 3 provide important information about levels of anxiety, depression and distress in cancer patients. IQoL instruments also provide details on quality of life issues that are important to individuals in terms of how they perceive their quality of life. However, it is concluded from this review that the inclusion of interviews in data collection procedures, particularly clinical trials, would be useful in providing information that is comprehensive and patient-centered. This type of information increases the understanding and meaning of study findings for health care staff, thus increasing its applicability to clinical practice.

#### **1.4 Aims of the Study**

The main aims of this study are to test the null hypothesis that ‘Open Window’ has no effect on participants’ levels anxiety, depression and distress over time and explore how it may have influenced their experience of undergoing stem cell or bone marrow transplantation.

#### **1.5 Methodology**

Chapter 4 discusses why a research design encompassing a randomised controlled trial with mixed methods for data collection and analysis was considered the most appropriate for this study. The use of both questionnaires

and semi-structured interviews provides subjective data on participants' experience of 'Open Window' and also allows any psychological effect to be measured over time. The psychometric tools chosen to measure any psychological effect were The Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983) and the Distress Thermometer (DT) (Roth et al. 1998). A 30-item survey questionnaire, known as the 'Open Window' questionnaire, was designed to assess participant views and experience and a fourth questionnaire, the single-item 'Expectations' questionnaire was used to determine if 'Open Window' affected participants' overall experience of having a stem cell or bone marrow transplant.

Stratified probability sampling was used in this study and all patients over the age of 16 years, undergoing allogeneic and autologous stem cell or bone marrow transplantation were eligible. The total sample size for those who underwent allogeneic transplant was 39 and those who underwent autologous transplant was 29 which represents 19.5% and 14.5% respectively of the total number necessary to provide sufficient power which was calculated at a total of 400 participants. The ethical principles of Beneficence, Non-Maleficence, Informed Consent and Justice provided a framework for identifying issues relating to the protection and respect of participants in the study.

## **1.6 Methods**

The methods used in this study reflect the pragmatic philosophy of mixed methods research. Chapter 5 provides a detailed account of how I prepared for the study by preparing other health care staff involved in or affected by the study, for example transplant co-ordinators, nurse managers and cleaning staff. Rationale for the necessity for two pilot studies is provided along with detail relating to the relevant considerations and decisions surrounding the choice of each method in the research process.

Chapter 5 outlines the rationale for 7 data collection points in the study and the procedures for recruitment, data collection and analysis. Quantitative and qualitative data were stored, managed and analysed with the assistance of SPSS version 15 and NVivo 7 respectively. The main statistical tests used to analyse the quantitative data were crosstabulations, chi square for independence, and repeated measures ANOVA. Template analysis was used to analyse the qualitative data.

## **1.7 Results and Discussion**

In terms of the qualitative results, this study provides a comprehensive picture of living with a life threatening illness and the experience of having a stem cell or bone marrow transplant from a patients' perspective. As expected the main themes emerge from the predetermined topics included in the interview discussion. However, an unexpected and surprising theme called 'Self and Others' also emerged. These data provide detailed explanations for how patients adjust psychologically to having a life threatening illness but also clearly indicate the central role that immediate family and trust in the medical and nursing staff play in how they experience the transplant, their recovery and return to normal life.

It is important to note that the quantitative results presented are based on  $\frac{1}{3}$  of the sample required to reach adequate power. The thesis presents the interim analysis only as this study is continuing for a further 2 years. Results presented in chapter 6 indicate that 'Open Window' does not have a statistically significant effect on participants' levels of anxiety, depression and distress over time, regardless of age, gender or educational level, even though the intervention samples indicate slightly lower scores for all three outcomes than the control samples. However, a statistically significant difference ( $p=.008$ ) is evident between the overall scores for the intervention and control samples in relation to their expectations of having a stem cell or bone marrow transplant with the intervention groups reporting that their experience was better than expected.

Given the randomised controlled design of this study, it is possible to attribute this difference to their experience of 'Open Window'. Qualitative data indicates that participants felt the value of 'Open Window' was in its ability to distract them from their immediate physical and psychological situation and connect them with the outside world. The 'Open Window' survey questionnaire supports this and patterns that emerged in how participants used it and discussions in chapter 7 suggest that they experienced 'Open Window' in a similar manner to how the public experience art in a museum. This is also supported by the findings from the qualitative data which indicate that participants commented freely on their likes, and dislikes, about 'Open Window' and how it made them feel. This theme is referred to as appreciation of art. The use of the remote control ensured that participants created their own experience and literature suggests that their return to view 'Open Window' on average, 3-4 times a week indicates that it held aesthetic appeal and personal meaning for them.

Overall scores in the HADS and DT were relatively low, below the cut-off score recommended for treatment, with no differences seen with age, gender or education level. This suggests that participants were quite well adjusted psychologically to being diagnosed with and undergoing treatment for a life threatening illness. The qualitative data provide some explanation for this with the emergence of an unexpected main theme called 'self and others'. In this theme, participants talk about the importance of family as a source of support, positive relationships and the recognition of their own inner strength. Participants also indicated in the qualitative data that although some experienced acute episodes of stress, it was not perceived as a problem and many commented that they perceived that they had either complete control or some control over their lives. Even those that did not perceive that they had control did not view this negatively. Given that the literature identifies the presence of both stress and control as important factors in whether or not cancer patients experience anxiety, depression and distress, the qualitative data further support and explain the low scores for anxiety, depression and distress.

This study recommends that the role of the family in patients psychological care receive more emphasis in undergraduate and postgraduate education for health care staff. Studies on both medical and non-medical interventions need to include mixed methods as a means of providing clarity and explanation to quantitative data but also for uncovering new or previously unexplored subjective data. The value for 'Open Window' in distraction, providing a sense of connection with the outside world and in art appreciation suggests that sense of self is strong and life outside their illness is very important to patients.

## **Chapter 2: Literature Review**

### **2.1 Introduction**

This chapter provides a review of the literature relating to four key concepts underpinning this study. These include: health care environments, art and design, art in health care, and living with a life threatening illness. The main theories used to explain and understand the physical and psychological context in which this study is taking place, are also presented in this chapter.

The ‘Open Window’ study is concerned with evaluating how patients psychologically respond to and experience art that is intended to be an integral part of their treatment while undergoing a bone marrow or stem cell transplant. As ‘Open Window’ is a novel art intervention, a review of art in health care contexts will be presented with particular attention to the definition of art as proposed for this study, and why it is regarded as potentially an essential component of the psychological care of patients with a life threatening illness.

### **2.2 Health Care Environments**

The influence of modernism on healthcare environments is manifested by bare walls, very bright lighting, noisy communication systems and technology throughout hospitals. This is accompanied by a sense that modern hospitals prioritise the treatment of the illness or disease, rather than the treatment of the patient, and reflect concerns such as cost and efficiency as a primary focus in the funding and design of healthcare facilities. Ulrich and Staricoff et al. (2005) suggest that such environments are stressful and can have a negative influence on patients’ emotional well-being, which is already compromised by their illness. This is a worrying trend considering Florence Nightingale’s (1863) view, approximately 150yrs ago, that the first requirement of hospitals is not to harm patients.

It is generally regarded as common sense that the environment or 'space' that human beings occupy at any one time affects them physically, psychologically, sociologically and emotionally (Malkin 1992, Bilchik 2002, Schweitzer et al. 2004). The concept that the health care environment in which patients are treated and cared for can have a positive or negative effect is not a contemporary one. The ancient Greeks built temples to Aesclepius, the God of Health and Healing. Temples were designed to promote physical and psychological healing through the use of nature, light, music and art (Ruga 1992, Schweitzer et al. 2004). As recently as the nineteenth century, Florence Nightingale (1863) recommended that sunlight, calm atmospheres, views of nature, colour and beautiful objects were as essential as hygiene and warmth in hospitals. She was regarded as the greatest influence in hospital architecture for more than a century (Thompson and Goldin 1975), used statistics to support her arguments and was the primary advocate of the 'pavilion' design of many hospitals of that era. However, in the 20<sup>th</sup> and 21<sup>st</sup> century, hospital design was dictated by greater emphasis on treating the illness and disease rather than the person, and striving for ever increasing efficiency in treating larger numbers of patients in the timeliest and most cost efficient manner (Gesler et al. 2004). Higher quality building materials and the increased use of antibiotics meant that hospitals could treat more patients in more confined spaces and high density buildings (Williams 1992).

Over the past twenty years, perhaps primarily due to the influence of a study by Ulrich (1983), many architects and health care professionals are beginning to see that the ancient Greeks and Florence Nightingale might have got it right in relation to their belief that environments contribute to healing the person and not just the illness. Ulrich (1983) reviewed the records of forty-six patients who underwent cholecystectomy on one unit over a nine year period. Twenty three patients were nursed in a room with a view of trees and the other twenty three patients were nursed in a room where the windows looked directly onto a brick wall. The information recorded for this study included: number of days in



hospital, amount and frequency with which analgesia and medication for anxiety were required each day, minor complications and nurses' notes on patients' recovery.

The findings suggested that patients with the view of trees had a shorter stay in hospital (0.74 of a day); appeared to experience a more positive recovery (based on comments in the nursing notes) required less analgesia and had fewer minor post-operative complications although the difference between the two groups was reported as not statistically significant. There are a number of limitations to this study, some of which Ulrich (1983) documents. However, the main limitation is that although it includes a specific patient group, it is a small retrospective, uncontrolled study, and therefore, its findings are questionable. Also, Ulrich's (1983) most referenced finding that views of nature shorten the length of stay in hospital following a cholecystectomy is questionable because 0.74 of a day difference could be influenced by the time of day the patient was discharged and collected from hospital by relatives; this is not discussed in the research report. A larger randomised controlled trial would produce more rigorous findings. Ulrich's (1983) study is extensively and often uncritically referred to in the literature and, although limited, is perhaps primarily responsible for the growing interest in the influence of art and design in modern healthcare environments. The overall lack of statistical significance of the findings from Ulrich's (1983) study may not be as important to health care providers, architects and managers as the possible clinical significance of the findings. The patient is now considered, if not consulted, in the design and planning of many health care settings. The implications are that, although cost and efficiency remain a primary concern to hospital architects, other factors such as art and design are regarded as key ingredients in providing spaces for patients that are comforting, relaxing and welcoming.

A study by Beauchemin and Hays (1996) investigated whether exposure to natural light shortened the length of stay in hospital for patients with severe and

refractive depression. The study took place in a unit where rooms containing 17 beds had full unimpeded sunlight throughout the day. The remaining rooms had 17 beds that did not have direct sunlight because of an adjacent building, and lighting was dull. Records on 174 admissions indicated that patients in the brighter rooms were discharged after 16.9 days and those from the dull rooms were discharged after 19.5 days resulting in a difference of 2.6 days that was consistent over the seasons. The authors acknowledge the limitations of this study in that it is retrospective and uncontrolled and therefore, unreliable, and they describe the findings as being of theoretical interest only. Nonetheless, its findings show similarities with Ulrich's (1983) study, therefore, it is useful for indicating the possible response of patients to their surroundings, in particular light and nature.

The biophilia hypothesis is one probable explanation for human beings' positive or negative response to nature. Some literature (Ulrich 1992, Bilchik 2002) asserts that since the beginning of human evolution, human beings have a visceral, innate need to be responsive and sensitive to the environment. Another view is that biophilia is driven by the environment, personal experiences and culture (Kahn 1999, Clayton and Opatow 2003). However, regardless of the belief about the origin of biophilia, all agree that it is this that drives a persons' preference, regardless of age or gender, for access to being in or looking at landscapes (natural) rather than a concrete building. Happy/kind human faces and non-threatening animals are thought to have the same effect (Ulrich 1991, Ulrich 1992, Kahn 1999, Bilchik 2002). People living in natural settings are healthier than those who do not (Kaplan and Kaplan 1989) and homes or properties with a view of water or landscapes are more popular and expensive than those without a view. The biophilia hypothesis is relevant to the curative process in the 'Open Window' project and may be evident in the feedback participants give in relation to what they see and what they would like to see.

The United States of America appears to be well advanced in the development of healthcare environments that are comfortable, welcoming and patient focused as, for example, the ‘Pebbles Project’ (Center for Health Design 2006) and ‘Planetree Alliance’ (Thieriot 2003). The Pebbles Project was established about 15 years ago for the purpose of exploring how healthcare design can provide a healing environment. The emphasis is not just on how healthcare designs function but also how the environment feels. A number of health care organisations have joined this project and are committed to evaluating how design and planning affects the care that patients receive in these environments. Access to nature, natural light and landscape views are incorporated into the designs, and art works and music are used to reduce stress. The Planetree Alliance comprises healthcare organisations that recognise the human need for interaction with their environment and other people and incorporate this into healthcare designs that are homely, comfortable and welcoming. Music features as a key factor in providing a healing environment with this organisation. However, the American advancement may not be due to Americans having a greater appreciation of art and design and its influence on the environment and people, but perhaps more so because the health service in the United States of America is commercially driven. It is necessary to give people what they want and find aesthetically pleasing in order to attract them (for treatment) and provide effective patient centered treatment and care in comfortable, welcoming and stimulating environments. Otherwise, according to Sadler (2004, 3) “these hospitals will have to suffer the economic consequences in an increasingly competitive and demanding economic environment”.

A survey conducted by the Society of the Arts in Healthcare together with the Joint commission on Accreditation of Healthcare Organisations and Americans for the Arts reported that over 2,500 hospitals use arts programmes to create healing environments, provide psychological support for patients and communicate health information (Le Tourneau Gore 2005). Seventy-seven percent of US hospitals responded to the survey. Introducing the concept of

design and art as a strategy in improving the quality of patient service is, of course, much easier when it is manifest in increased business and profits. This is not a factor in countries where healthcare is currently regarded as a basic human right and is free at the point of delivery; therefore, the monetary benefits of such interventions are not crucial to the survival and development of the healthcare institution. According to Monk (2004) this results in the aesthetic needs of patients being frequently neglected. That said, in Ireland and many European countries, government policy exists that allows for 1% of the cost of building and maintaining a health care institution to go to art works and projects, demonstrating that the value of art in healthcare is somewhat recognised (Department of Arts sports & Tourism 2004). However, ongoing art projects and indeed employment of arts officers or directors in hospitals are generally funded by Arts Council Grants through hospital trusts administered by arts committees. Even when art projects are funded outside of normal hospital budgets, usually through charitable donations, they are still heavily criticised (Perry 2005, Sky and News 2005). The implications are that other than being ‘nice to look at’ art appears to be regarded as a luxury and is not valued by the general public as having the capacity to help people in any way. This re-enforces the need for rigorous, research-based evidence on the physical and psychological effect of art in health care contexts.

An evaluation by Francis et al. (2003) of the King’s Fund’s Enhancing the Healing Environment Programme in the United Kingdom indicated that through an innovative, inclusive approach to developing arts and design projects, therapeutic benefits were evident. These included improved communication, interaction and creation of a positive ambience in which patients and staff had greater feelings of calmness and well-being, and patients perceived that they had a positive experience. This report describes the art and design projects in great detail and clearly outlines the process for inclusion in the programme; however, although the authors indicate that the evaluation used a qualitative design

including observation, team interviews (initially) and focus groups, more detail is needed to demonstrate the credibility of this evaluation.

### **2.3 Art and Design**

It is evident from the literature that the concepts of art and design are used synonymously in discussions on healing environments and healthcare (Duncan 2001, Davis 2001, Ulrich 2003, Parker et al. 2005). However, although both art and design have a visual dimension to their form, they are quite distinct in concept, expression and purpose. Environmental design refers primarily to the use of space, light, shape and materials to develop physical, spatial environments (interiors and/or exteriors) to meet a particular functional need or create a specific experience (Nathan 2008). According to Vitruvius, a well known architect from ancient Rome, a building should have ‘firmness, commodity, and delight’. Modern interpretation of this is that a building should stand up, should have a purpose and should be aesthetically pleasing (Mayne 2006). In relation to the design of hospitals, these principles were upheld until, as discussed earlier, the introduction of antibiotics and higher density building in the 20<sup>th</sup> century. Thereafter hospital building became clinically functional and efficient with a greater emphasis on reducing costs and treating as many patients as possible. Making hospital buildings aesthetically pleasing was not a focus of architects, health care managers and government agencies involved. Gesler et al. (2004, p3) suggest that this is not the fault of the designers and describes hospital buildings as “sites that reflect and constitute complex social power relations” with the outcome reflecting the degree to which the various stakeholders were able to compromise on health beliefs and differing priorities and agendas. The term ‘architecture’ may only apply to buildings designed for aesthetic appeal but as Monk (2004) points out in relation to hospital design and building, what is aesthetically pleasing to a designer may not be for a patient or staff member. He suggests that all well designed hospital buildings should have the aesthetic power to ‘elevate the spirits and create a pleasurable feeling’ regardless of individual

preferences (Monk 2004, p33). He concludes that, contrary to the views of those charged with organising the design and building of hospitals, ‘good design may not cost less but it need not cost more either’ (Monk 2004, p33).

In an attempt to define art for the purpose of providing clarity for the reader, it became clear that this would not be a straightforward matter. Books have been written that analyse theories and philosophies of art in an attempt to define it (Carroll 2000, Davies 2006); however, both of these authors and indeed others (Weitz 1956, Danto 1997) conclude that it cannot be defined or should not be defined because it lacks an essence in terms of which it can be defined. The implication is that definitions set boundaries and limits that are not compatible with the art or acceptable to artists, therefore, it cannot or should not be defined. However, for those without knowledge or understanding of art theory or philosophy, a working definition is required purely as a frame of reference or starting point. Muelder Eaton (2000) provides such a definition in which she suggests that a work of art is an artefact that is treated in aesthetically relevant ways; has a cultural basis and requires a creative perception and/or reflection by both the artist and the viewer. This working definition is particularly relevant for the ‘Open Window’ project in explaining its concept, structure and content, not just for participants in the study but also the health care staff involved or interested in the project.

These working definitions of art and design demonstrate the marked differences between both concepts and suggests that discussing art and design as synonymous is misleading and possibly detracts from the equal value and benefit that both have for improving patients’ health care experience. The discussion that follows in the next section on art in health will show that, while consideration of both concepts may be essential in helping patients, they each have a unique value.

## **2.4 Art in Health Care**

Historically, visual art has always been present in hospitals although the reason for this was to impress hospital governors, lords and ladies, rather than a concern for the well-being of patients. In recent years music, visual and indeed the performing arts have become regarded as key factors in the creation of healing environments and providing patient-centred care (Kenyon 2003, Homicki and Joyce 2004, Mitchell and Dose 2004). The term 'healing environment' refers to the concept of treating and caring for a person as a 'whole' and acknowledges the uniqueness and needs of each individual in the process of architectural and interior design and the incorporation of art in planning and developing healthcare institutions. These environments are welcoming, comfortable, stimulating, reduce stress and provide positive distraction for patients. This is not a new idea and even today art, whose value in health lies in its ability to comfort, console and sustain (Wikoff 2004), is thought to reduce stress and anxiety levels, and promote well-being and a positive mood (Staricoff et al. 2001, Schweitzer et al. 2004).

A qualitative study by Hodges et al. (2001), based on hermeneutic phenomenology, investigated the feasibility of integrating masterworks of art with a programme of care for chronically ill older people. Group interviews were conducted across seven focus groups comprising a total of 65 participants. The findings indicated that using masterworks of art provided a medium for communication between patients and caregivers that transcended age, facilitated shared understanding of the patients' reality and fostered interpersonal engagement in the patient. The authors of this study recommend that further research is required to explore such interventions; however, these findings suggest that the value of art in healthcare lies not just in its aesthetic appeal but also in its ability to facilitate communication that is patient centred. This will have a positive impact on how patients perceive the quality of care they receive. This is echoed by many authors (Kenyon 2003, Mitchell and Dose 2004, Homicki and Joyce 2004, Staricoff et al. 2005).

A further study by Ulrich et al. (1993) explored the effects of photographs of nature scenes, abstract art images or nothing on patients' recovery from cardiac surgery. Six groups of patients were exposed to a different picture placed at the foot of their bed. The findings indicated that patients exposed to the nature photograph experienced less post-operative anxiety than those exposed to the other types of art images. Of note in this study was that patients responded so negatively to the abstract images that they were removed immediately. However, the abstract images were computer generated which raises the issue of the importance of using appropriate art in the health care environment. Ulrich (2005) acknowledges this but suggests that from a patient perspective what is important is whether the patient responds positively or negatively to the image. Placing the images at the foot of the bed is an unusual location even if the patient is recovering post-operatively and this may also have affected their interpretation of the images. These findings support the biophilia theory discussed earlier in this chapter which suggest that people prefer images of nature. The suggestion by Ulrich that having a response to art is what is important and not whether it is a positive or negative, is interesting and will be discussed in more detail later in this chapter when attempting to provide a theoretical framework for understanding the psychological response to art in a health care context.

A large study of the effects of the visual and performing arts in healthcare by Staricoff et al. (2001) included an evaluative survey using a specifically designed questionnaire and was conducted from April 1999 to April 2000. One thousand and one people comprising patients, staff and visitors completed the form that assessed their responses in relation to a) visual art, b) performing arts, c) general environment and d) value of the work of the Chelsea and Westminster Hospital Arts Programme and the role of the arts in the healing process. People were asked to evaluate the permanent display of contemporary art and the weekly/daily live performances of music, theatre, dance and poetry. The findings indicate that 75% of patients, staff and visitors reported that the visual



and performing arts reduced stress levels, had a positive effect on their mood and were a positive distraction. Live performances were reported by all as being more positively distracting than visual art. Two thirds of patients, staff and visitors rated the value of Chelsea and Westminster Hospital Arts and the importance of the arts in the healing process very highly. This report does not include detail on how respondents were selected to complete the questionnaire and how many chose not to participate. It is, therefore, feasible to suggest that patients, staff and visitors with a particular interest in visual and performing art responded and, therefore, the results may be biased. A randomised approach to participant inclusion could have prevented this. Also, while the authors give some detail in describing the performing arts content, no detail is given on the visual art content or context in the report.

The second phase of Staricoff et al's (2005) study investigated the psychological, physiological and biological responses of patients to visual and performing art and the influence on outcomes of treatment. A quantitative design using controlled blind or double-blind approach was used. Participants were assigned to the control group if they attended a clinic or received treatment in an environment that did not have visual art or music. The study group was formed by participants who attended a clinic or received treatment in the same environment but this time in the presence of visual art or music. Psychological outcomes were assessed by measuring levels of anxiety and depression pre and post test using the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983). Depending on the purpose of the clinic or the treatment being received, physiological and biological outcomes were assessed by measuring levels of blood pressure, pulse, cortisol and immunoglobulin A levels and CD4 and CD8 cell counts. The medical/surgical day unit, antenatal/postnatal and high-risk clinic, maternity, trauma/orthopaedic and HIV/AIDS clinics were used as research units in the study. The effect of visual arts and music was also evaluated by assessing the length of stay in hospital, amount of analgesia and anaesthesia required and the amount of induction agents prior to anaesthesia.

The overall findings indicated that participants in the study groups reported lower levels of anxiety and depression and improved quality of service, required lower levels of analgesia and anaesthesia and had lower lengths of stay in hospital than those in the control group. Monitoring of blood pressure, pulse and cortisol revealed lower levels in the study group than the control group; however, the authors of this study acknowledge that the cortisol differences could be a seasonal effect as the levels were recorded over winter and spring. Although this is a comprehensive study there are a number of limitations to which the authors refer. The first is that although power analysis was conducted prior to starting the study, the number of participants required to achieve power does not seem to have been achieved, therefore, it is not possible to say that these results occurred only as a result of the visual art and music and not just by chance. The authors do not, however, state what sample size was required by the analysis. The second limitation is that findings are generally reported as not statistically significant. The authors suggest that the findings are, however, clinically significant. This is an important point from the perspective of the caregivers and the patient and is worthy of further consideration by health care providers in an attempt to provide positive and patient-centred healthcare environments. The third limitation is that the participants were not randomised to the study or control group and the authors do not clearly indicate how they addressed the issue of bias in the study, although they do acknowledge that randomisation would have been the preferred way of allocating participants. An interesting aspect of this study is that the art works are not described. Benson (1993) highlights a similar limitation in O'Hare's (1981) study where no information was given in relation to the art and poetry used in the study. The consequence of this is that the responses or findings in the study are not a complete representation of what happened between the individual and art work. It implies that the art work is almost irrelevant to the whole experience. According to Benson, the person and the art are essential and equal parts of the experience. The absence of descriptions of the art work in research on this topic in health

care settings is apparent from all the art based studies evaluated for this review and (Scher and Senior 2000) imply that there is perhaps a misinterpretation of the role that art has in a patient's experience.

Diette and Rubin (2003) used a randomised controlled trial design to determine whether distraction therapy using 'Bedscapes' (nature sights and sounds) ([www.bedscapes.com](http://www.bedscapes.com)) during flexible bronchoscopy reduces pain and anxiety. Participants from the intervention (n=41) and control (n=39) groups were asked to indicate how well their pain had been controlled during the procedure (i.e. poor, fair, good, very good or excellent) and anxiety was measured using a six-item instrument from the Spielbergen State-Trait Anxiety Inventory. Data were collected prior to the procedure as a baseline and then again after the procedure. The findings indicated that pain control was more effective with the intervention group than the control group. However, there was no difference in patient reported anxiety between the two groups. The authors recommend further research into the precise mechanism of this beneficial effect. Interestingly, the title of this paper includes a reference to the intervention as a 'complementary approach to routine analgesia', yet the discussion refers to the intervention as an 'alternative' therapy to medication. This is quite a unique view of the role of art in healthcare and one that is not echoed in the literature. Art is generally presented in the literature as an integrated part of the environment and, therefore, is not considered as either alternative or complementary to patient treatment or care. Even though art comes in many forms, it is always a subjective experience. Perhaps the role of art in healthcare is about valuing holism and recognising the uniqueness of patients and their individual needs within the context of treating their illnesses in a highly regulated healthcare system.

Scher & Senior (2000) suggest that anecdotal and uncritical reporting of the role and value of art in health needs to become evaluative reporting and provide critical evidence of its effect and value. They conducted an evaluative survey of the Exeter Health Care Arts Project to assess the effect of specific art works on

the hospital experience of patients, staff and visitors and gather opinions about the Exeter Health Care Arts Project. Three hundred and seventy eight people comprising patients, staff and visitors completed a questionnaire. The findings indicated that about 80% of the participants noticed the art pieces in their environment and supported the project. Approximately 20% of patients reported that they had not noticed the art works and as this study did not ask if the art work had an influence on the environment, it is impossible to determine if the art influenced the patients' experience directly or indirectly. Participants were instead asked to assess the artwork using predetermined descriptors so it is questionable as to whether it is possible for this study to achieve its aim of assessing the effect of artworks on participants' experiences using these instruments. About half of the staff indicated that they did not think art had a therapeutic effect and about one third felt that art reduced stress and was a positive distraction. This is a unique study in that it asks patients to evaluate the art works placed in their environment. This is important for artists and healthcare managers in planning and budgeting for art projects and is the only study that has attempted to do this. However, this study would have provided a more comprehensive idea of how art influences the healthcare environment if patients and visitors had been asked how the art made them feel and how it influenced their environment.

Behrman (1997) suggests that it could be difficult to provide rigorous proof of the effects of the arts on healthcare outcomes as there are too many variables to do a trial that is statistically reliable. This remains debatable as much of the research to date is not well controlled and can not be applied to wider populations. The absence of rigorous evaluation of the value of art in health, results in uncertainty in relation to its benefits, harms and value for money (Hamilton et al. 2008). The use of a randomised control trial design and larger sample sizes would overcome these issues. Also, given the subjective nature of art and the need to provide rigorous evidence, the use of mixed methods for data collection, such as relevant psychometric tools, survey questionnaires and

interviews may allow all relevant variables to be measured and identified respectively while also providing meaning and expansion with subjective data.

Prior to designing and conducting the ‘Open Window’ study, it was important to understand the theories underpinning the whole context in which it took place, which included theories explaining people’s psychological response to art and their environment. The context refers not only to the physical environment in which the study takes place but also the very particular life threatening situation in which the participants exist. These three issues, the psychological effect of art, the participants with a life threatening illness and the physical environment form the main components of the theoretical framework of this study. The theories used to develop and explain these issues are Benson’s (1993) theory of aesthetic absorption, Brennan’s (2001) theory The Social-Cognitive Transition (SCT) model of adjustment and Benson’s (2001) ‘Cultural Psychology of Self’. These theories will be used to develop discussion on the findings and where relevant throughout the thesis.

#### 2.4.1 Theory of Aesthetic Absorption

The question of why an art intervention was considered appropriate in helping patients psychologically needed to be clarified prior to commencing the study. It is evident from the literature that there are very few studies that examine the role of art in health, usually it is explored in terms of art and design with only superficial reference, if any, as to why it may help patients. Benson’s (1993) theory of aesthetic absorption was considered fundamental in explaining, clarifying and justifying why ‘Open Window’ could be a useful intervention in helping patients psychologically.

Benson’s (1993) theory called ‘aesthetic absorption’ is presented in his publication, ‘The absorbed self’ and centers on psychology and philosophy as a means of exploring art and experience. Benson (1993) classifies psychologies as ‘top down’ or ‘bottom up’. ‘Bottom up’ psychologies have the advantages of

control, experimental analysis and verification generally favoured by psychologists. In contrast 'top down' psychologies focus on experiences and the language used to describe these experiences. This type of psychology also invites collaboration with other disciplines, such as philosophy and it is this partnership upon which Benson's theory of aesthetic absorption is based. He believes that an adequate psychology of art needs to be grounded in a philosophy of experience, and uses a combination of Dewey's (1859-1952) pragmatist philosophy and aesthetics to frame his theory of 'aesthetic absorption' critically and comprehensively. He defines this as "Losing oneself when looking at a picture or reading a novel" (Benson 1993, p. ix) but that the observer and art work are unified in the creation of a new holistic experience comprising the individual, the context and the art work. The term 'absorption' refers to the initial exposure to the art work where the individual has not yet attempted to think about or analyse what they see or hear.

Benson (1993) suggests that the psychological perspective on art is generally limited and excludes the notion that the engagement of a person with art is reciprocal and not unidirectional from the person to the art work. Aesthetic absorption requires engagement with and openness to one's environment and possible experiences in which points of view, feelings, perceptions, interpretations and sense of self may change. Benson acknowledges that subtle or covert content in art can therefore manipulate and control the viewer and this can be a positive or negative experience. He also points out that everything that makes us unique as individuals and from which we attain our sense of self is what we learn from others in social contexts. This view is supported by Maclagan (2001, p10) who describes aesthetic experience as "a far more fundamental and inescapable aspect of experience" and forms the basis of "our capacity to inhabit works of art imaginatively that contribute to the richness and depth of life. This implies that we are open to this manipulation in all areas of life and perhaps do not have as much control as we think we have.

A key aspect of Benson's theory of aesthetic absorption is that it is a process that requires contemplation by the viewer. It is a personal choice, active and creative and this needs to be considered when addressing the purpose of art in health care contexts where it is generally regarded as a pleasant distraction and means of enhancing the environment. Benson's view on this is that to consider art as a distraction is to attempt to control the viewer and, while some level of absorption may occur, it is not patient-led and does not result in new experiences or situations for the patient. Aesthetic absorption represents the beginning of a journey for the viewer in which they continue to engage in, reflect on and formulate meaningful and unique personal experiences. This means that the person does not revert to their original situation or experience but, to a greater or lesser degree, they have moved on to a different one (Benson 2001). Benson's theory identifies a process that occurs between a person and art that is fundamental for the provision of care that is truly holistic for patients with a life threatening or chronic illness.

## **2.5 Living with a life threatening illness**

A diagnosis of cancer is an emotionally distressing and disturbing experience for a person (Roth et al. 1998, Hoffman et al. 2004, Lee et al. 2005). The disease itself and the treatment adversely affect every aspect of a person's life. Many patients, especially in the early stages of diagnosis and treatment experience anxiety, distress and depression. The severity of these symptoms varies depending on the stage of the disease and treatment. Measuring levels of anxiety, depression and distress using psychometric instruments such as the HADS, BDI and Distress Thermometer indicates whether a person has developed mental illness or whether they have psychologically adjusted to their illness (Brennan 2001). The term 'adjustment' is widely used in psycho-oncology and refers to the "absence of psychological morbidity and a return to premorbid functioning" (Brennan 2001, 1). Adjustment disorders refer to significant emotional or behavioural symptoms, such as anxiety and depression, in response to a stressor (Akizuki et al. 2003, Brennan 2001). Social cognitive theory

presents the view that human behaviour and functioning is driven by the dynamic interaction of personal, behavioural and environmental influences (Bandura 1986). This theory presents the idea that a persons' behaviour is not influenced directly by environmental and social issues. These factors instead influence individual values, beliefs, feelings and overall sense of self which in turn affects self-efficacy beliefs, emotional states and personal aspirations. However, underpinning this theory is the notion that human beings are masters of their own destiny and it is this that allows people to adapt to changing and challenging social, economic and environmental influences (Bandura 1986).

Although Brennan (2001) accepts that this theory is useful in explaining key aspects to adjustment to a life threatening illness, he suggests that it does not account for why some people adjust reasonably well or at the very least emerge from the experience with the ability to reconstruct their sense of self and their lives, yet others are unable to do this and develop psychological disorders or persistent and high levels of distress.

Coping theory is also often used to explain how and why people respond in certain ways to having cancer. It describes the process of dealing with personal and external influences that an individual may view as challenging or difficult (Lazarus and Folkman 1984). This theory suggests that individuals have a coping style that they tend to use consistently in response to difficult situations in their lives. It is almost like a personal characteristic; for example, a person who is undergoing treatment for cancer can be described as having a 'fighting spirit' or 'not dealing with it'. Coping theories are criticised due to their primary focus on the individual without giving attention to the influence of the social context or environment on how a person adjusts to a life threatening illness. It is well documented that people with more social networks and support tend to adjust positively to cancer diagnosis and treatment (Kreitler et al. 2007, Rodrique 2007). Furthermore, coping theory does not help to explain the different ways in which a person deals with various stages of the disease, for example a person



who has just been diagnosed may react very differently to their illness at a later stage in their treatment (Brennan 2001). Spiegel (1997) criticised coping theories because they do not adequately incorporate the meaning of the reality of having a life threatening illness for individuals. Therefore, instead of attempting to identify specific and individual 'coping styles' it may be more appropriate to take a holistic or integrated view of what the patient with cancer is experiencing.

A small (n=10) qualitative study by Xuereb and Dunlop (2003) reported that coping with leukaemia and bone marrow transplantation is directly related to the meaning and agency a person has for leukaemia. The meaning of leukaemia for individuals is related to their values at the time of diagnosis and not just the objective stages of a medical condition and its treatment. Agency refers to a person's life-long pattern of dealing with challenge and the tendency, therefore, to use strategies and resources that they are skilled in or with which they are familiar. White (2004) supports this view and the implication that a person's psychological response to cancer diagnosis and treatment is multi-dimensional.

### 2.5.1 'The Social-Cognitive Transition' (SCT) Model of Adjustment

Using concepts that emerged from the literature in relation to coping theory, social-cognitive theory and traumatic stress theory Brennan (2001) developed 'The Social-Cognitive Transition' (SCT) model of adjustment. This model was developed in response to a limitation in the social-cognitive model's ability to explain why some people who are diagnosed with cancer adjust successfully and others develop adjustment disorders. The SCT model of adjustment is based on the premise that humans are self-regulating systems that learn and develop from experiences. These experiences, within the context of social and cultural influences, result in the development of what Brennan (2001) refers to as a person's 'assumptive world'. It presents the view that adjustment is a dynamic ongoing process of adaptation to the many new and difficult experiences a person with cancer has over time. White (2004) supports this view and suggests that an experience such as cancer diagnosis can be negatively perceived initially but over

time this may change and a person may perceive that they have benefited from their experience. The SCT model of adjustment comprises 4 key components which include 'life trajectory', 'beliefs about the self: control and self-worth', 'nature of attachments', and 'spiritual/existential'. Brennan (2001) presents each of these themes in terms of their core assumptions and how a positive or negative transition manifests in the context of cancer diagnosis and treatment.

Brennan (2001) acknowledges that although the broad nature of psychological theory underpinning this model allows for empirical testing of the model, specific psychometric tools that measures how a person's core assumptions are affected by a life threatening illness do not exist. He proposes that Individual Quality of Life instruments are more congruent with the SCT model of transition than those that focus on health related quality of life. However, when one considers the individual and existentialist nature of adjusting to a life threatening illness (Spiegel 1997, McClain et al. 2003, Laubmeier et al. 2004), the relevance of using any psychological measurement tool, whether regarded as appropriate or not, is questionable. Perhaps a more appropriate method is using interviews to elicit views on how individuals adjust to having a life threatening illness and what were the main (positive and negative) influences on this process. This, in conjunction with the use of appropriate psychometric instruments, acknowledges the objective and subjective concepts that are part of the human experience of living with cancer.

The stress associated with having cancer or any life threatening illness is derived primarily from how it influences a person's sense of self and forces one to think about their own mortality (Moorey and Greer 1989). The SCT model of adjustment, and authors such as Janoff-Bulman (1992) and White (2004) suggest that having cancer challenges the assumptions that a person has about their world. Janoff-Bulman (1992) identifies the primary assumptions challenged by having cancer or any extreme life experiences are that the world is good and meaningful and the self is worthy. People assume that their lives have purpose

and are meaningful within the context of a world that “remains relatively constant, stable and seamless as does our sense of ourselves as points of reference to which all around us is referred” (Benson 2003, 24). Little et al. (2002) refer to this as continuity and suggest that it forms a central component of personal identity. These assumptions and sense of continuity allow for some flexibility in adjusting to new experiences but overall mean that life is generally predictable and stable. However, when a person has a life-threatening illness such as cancer these assumptions are in disarray, particularly in the early stages and while the individual tries to adjust.

Many qualitative studies support this view (Bertero et al. 1997, Landmark et al. 2001, Richer and Ezer 2002, Ramfelt et al. 2002, Lam and Fielding 2003). The study by Richer and Ezer (2002) explored the meanings that women undergoing chemotherapy for breast cancer gave to their experience. Using semi-structured interviews and a grounded theory approach, 3 dimensions to the experience emerged. These include ‘living in it’, living with it’ and ‘moving on’. The first two dimensions related to dealing with the more immediate impact of having cancer from an interpersonal and day-to-day perspective and the third dimension refers to the need to develop a new sense of their lives or new assumptions about life with which they are comfortable and which provide meaning. The ability to maintain or recover a sense of meaning and purpose to one’s life when diagnosed with cancer reflects successful or positive psychological adjustment (Brennan 2001, Johnson Vickberg et al. 2001). This translates into identifying and modifying long and short-term life goals in the context of their illness, having a sense of control not just in terms of their treatment but also their social and professional roles in life and redefining their view of human existence and their own mortality (Brennan 2001). However, adjustment disorders occur when a person cannot reconstruct their assumptive world or retain or develop a new sense of continuity and they develop reactive anxiety, depression or distress which has a negative effect on their quality of life. These responses are common in patients with cancer but do not mean that all patients suffer from anxiety,

depression or distress all the time. In the context of the SCT model of adjustment, it means that at certain stages in the course of an illness patients may experience anxiety, depression or distress but will move on as they adjust. Some patients may find this transition easier than others and the literature proposes that this is influenced by issues such as personality type, social support, age, gender, and environment (Folkman and Greer 2000, Ho et al. 2002). Keogh et al. (1998) conducted a longitudinal, prospective, repeated measure and mixed methods design study to investigate the psychosocial functioning of patients and relatives following bone marrow transplantation. They found that when a patient experienced physical improvement, the family and relatives viewed this as a sign that everything could get back to normal. However, at this stage patients were really only beginning to adjust psychologically to their experience. This caused tension as the family did not understand why the patient was not 'getting on with life'. Keogh et al. (1998) concluded that the experience of having a bone marrow transplant caused enormous disruption in family life and role performance and that a process of reintegration was required. This study is particularly relevant to understanding a patient's experience of living with a life threatening illness because it is one of the few that includes the family perspective. It, therefore, reflects a holistic representation of the patients' experience.

### 2.5.2 Global and Situational Meaning

The concept of constructing and reconstructing 'meaning' to self and one's life appears to be a key component in dealing with stress and adjusting to a life threatening illness. Park and Folkman (1997) suggest that there are two levels of meaning that they identify as 'global meaning' and 'situational meaning'. Global meaning is described as enduring "goals and fundamental assumptions, beliefs and expectations about the world" (Park and Folkman 1997, 116). It comprises three categories that include beliefs about the world, beliefs about the self and beliefs about the self in the world. The key attributes of global meaning are that it provides stability, optimism and personal relevance. Religion is an example of global meaning and explains why people either question their faith or rely

heavily on it to adjust to having a life threatening illness (Park and Folkman 1997). Situational meaning refers to how a person's global beliefs and goals interact with and influence a person's real experience of having a life threatening illness. There are three main aspects to situational meaning. The first is appraisal or assessment of the personal significance of how the illness affects the interaction between the person and their environment and occurs in primary and secondary stages. The second is the search for meaning in the situation and the third is the new or modified meaning derived from the experience. Similar to Brennan's (2001) SCT model of adjustment, Park and Folkman (1997) suggest that their theory on global and situational meaning reflects the dynamic and transactional nature of adjusting to major stressors such as a life threatening illness.

## **2.6 Self and the Environment**

This psychological theory is relevant to the discussion on living with a life threatening illness and Benson's (1993) theory of aesthetic absorption because it offers an explanation of the interaction that may occur between an individual and an art work and how this influences a person's sense of 'self'. Benson describes 'self' as a locative system that uses self-reference to travel within and between humanly created cultural worlds. Fundamental to this is the belief that "location is the ontological condition for all human beings. Not to be in a place is to be nowhere, and to be nowhere is to be nothing" (Benson 2003, 7). Cole (1999) suggests that cultural psychology emphasises how, through interaction with others, human beings are active agents in their self development though not usually in contexts of their own making. Benson's (2001) 'Cultural Psychology of Self' discusses the importance of understanding self in terms of being an ever present and dynamic concept that encompasses a physical aspect and social aspect in equal parts. He suggests that there is a fundamental link between the places that human beings occupy and how sense of self provides stability in these ever changing and evolving environments. This supports the SCT model of adjustment and introduces the relevance of the concept of adjustment (Brennan

2001). Cultural psychology is described as people working together, developing tools for living and constructing meaningful worlds and in doing this they evolve as individuals with a sense of self as part of these constructed worlds or environments. This is relevant to this study because in this particular health care situation, patients occupy environments that they have no control over and within the context of having a life threatening illness. The sense of self is challenged in an environment that is alien and because of protective isolation, could also be described as unresponsive. This, in addition to having a life threatening illness, further challenges a person's ability to maintain a sense of self and to modify or change their assumptions about the world; in other words, to adjust positively to their experience of having cancer.

## **2.7 'Open Window' Project**

### **2.7.1 Introduction**

'Open Window' is a unique and novel intervention for patients being treated for haematological malignancies in the 'National Adult Bone Marrow Transplant Unit', at St. James' Hospital, Dublin, Ireland. Treatment programmes include allogeneic and autologous stem cell or bone marrow transplantation for leukaemia and other haematological malignancies including lymphoma. On average, 951 new cases of haematological malignancies are diagnosed annually in Ireland (NCR, 2006). Not all require a stem cell or bone marrow transplant, but on average 70 allogeneic and 100 autologous transplants are conducted each year. This represents the total population of patients who received a bone marrow or stem cell transplant in Ireland. An allogeneic transplant is when patients receive stem cells or bone marrow from a related or unrelated donor. An autologous transplant is when the patient's own stem cells or bone marrow are harvested, treated and re-implanted a couple of weeks later.

### 2.7.2 National Adult Bone Marrow Transplant Unit

This unit comprises 21 single hepa-filtered en-suite rooms, with ante-rooms, in which patients are treated and cared for. The unit is located on the ground floor of a large hospital and the view out of most of the windows is limited to the light railway system at best and the air conditioning unit at worst. Windows in the rooms are quite large although light and sunlight is limited in some by an adjacent building. The rooms vary in size and shape and all are en suite and contain a bed, locker, easy chair and TV/video mounted high on the wall, usually to the left, in front of the patient. All rooms are painted in magnolia with a blue door to the en-suite and exit (Appendix 1). In order to reduce the risk of infection, flowers and pictures hanging on the walls are prohibited and personal items such as photos are limited. Blinds are used on the windows and bed covers are blue, pink or green. The overall effect is minimalist and clinical due to the presence of medical equipment. Visiting is limited and children under 14 years of age are not allowed to visit.

### 2.7.3 Protective Isolation

Although a new unit, The National Transplant Unit was not purpose built and the focus of the design was in providing a protective environment for as many patients as possible within a limited space and with very specific requirements. Entrance to the unit is via a locked entrance controlled by an intercom system. All staff and visitors are instructed to wash their hands on entering and leaving the unit and the patient's room. White plastic aprons are worn at all times by staff and visitors when entering a room. While it is arguable that the introduction of colour to the walls and the inclusion of patterned curtains or bedspreads might enhance the environment from a design perspective, in the absence of such an initiative, this atmosphere provides an ideal opportunity to assess the effect of art on the experience of a very specific group of patients in a controlled atmosphere. Redshaw (2004) suggests that design alone does not provide spaces that are attractive, imaginative and engaging but that it is the inclusion of art that does this. Her study on the impact of the provision of art in a children's hospital is

reported as providing a distraction for children and parents, providing enjoyment and comfort, facilitating self-expression and building self-esteem and confidence. This function of art in healthcare fulfills its role in providing a healing environment and is the primary reason why it was considered an appropriate intervention for the specific population of patients included in the 'Open Window' project.

Although the literature is limited, the effects of being treated and cared for in a restricted, carefully controlled environment for the purpose of protecting the patient against infection have been documented. Patients in isolation tend to experience higher levels of anxiety and depression and have lower self-esteem and sense of control (Gammon 1998); however, this study was conducted using patients in source isolation. These findings may not, therefore, be relevant to patients in protective isolation. Gaskill et al. (1997) conducted a study to explore the phenomenon of isolation from the perspective of patients in protective isolation whilst undergoing a bone marrow transplant. Data were collected using unstructured interviews and the main findings showed that patients perceived that their treatment, side effects and responses took priority over their feelings about their environment and protective isolation. All the participants tended to intellectualise the need for isolation and stated that they needed to be there in order to be treated and get better. As they responded to treatment and began to feel physically better, the window became important as a source of connection with the outside world and as stimulation for self-reflection. For some of the participants, the art work on the wall in front of their bed became a focal point and they used it to envision a life very different to the one they were experiencing. A qualitative study by Campbell (1999) similarly found that although patients had negative experiences while in protective isolation, they felt that it was just an essential part of the treatment in order to get better.



#### 2.7.4 The Introduction of ‘Open Window’

Due to the location, design and décor of the rooms, the patients in ‘The National Stem Cell Transplant Unit’ at St. James’s have very little stimulation other than TV, radio and reading. It is arguable that a patient-centred hospital environmental design may be sufficient to make their experience more comfortable and aesthetically pleasing; however, it is the inclusion of art in the environment that may provide a more positive and enduring distraction for patients and have a positive influence on a patient’s sense of ‘self’ and well-being and overall psychological adjustment to having a life threatening illness. It is in this context that ‘Open Window’ was introduced into the transplant unit on a pilot basis in February 2003. Development and installation of the ‘Open Window’ prototype was funded primarily by the ‘Bone Marrow for Leukaemia Trust’. This process involved ensuring that the technology met the required standards for safety and infection control policies in the unit. It was installed in two rooms initially and resulted in positive feedback from patients.

- “It really made me feel like I was taking a walk in the country side. I put it on an hour or so before I went to sleep because I liked drifting off to the bit where the reeds are swaying in the wind”
- “Yes, I got to like it even though I didn’t think I did like that kind of thing. It’s very relaxing, my Dad fell asleep watching it”
- “I didn’t like the music so I turned it off but one day I left the ‘open window’ on for most of the day”

Following the decision to conduct a clinical trial to assess the psychological effect of ‘Open Window’, funding from Vodafone Foundation Ireland ensured that further development of the prototype was conducted, resulting in the installation of an upgraded system in 8 rooms in July 2006.

‘Open Window’ is an entirely art based intervention comprising a multimedia system that uses a combination of video projectors, audio speakers and bespoke

software to make images appear as a ‘virtual window’ on the wall of the patients’ room (Appendices 1 and 2). Artists use mobile phone cameras and camcorders to record the images that are sent to the unit over the internet and via mobile phone networks. Original music composed for the project may also accompany the images as they appear. The curator and artist in residence on the project can discuss with the patient and family, the possibility of obtaining familiar and/or family images if they wish. These images are obtained in two ways. In the first instance the artist engages with the patients asking them to identify locations that are both significant to them and which they would like to view while they are in the unit. The artist then places a remote camera at this location, which relays images at a pre-specified time. In the second instance, the artist provides the family of the patient with a mobile phone camera and asks them to take pictures of places and objects that are of significance to the person from the family home and its environs. Patients can turn the system on, off and change the images by pressing the appropriate button on the remote control. They can also choose to include or exclude certain images if they wish. The volume of the music that accompanies some of the video channels can be controlled using the remote control.

#### 2.7.5 ‘Open Window’ as a treatment intervention

Artists are recognised as skilled in creating impressions or replications of the world for the viewer. These impressions, if executed with an appropriate degree of skill, can convey a sense of what it is actually like to be at the location that they are attempting to represent. With this in mind, the decision to develop ‘Open Window’ as an art based intervention was made. Artists are commissioned to create work for the ‘Open Window’ project and are aware of the nature of the viewer and the context in which the art will be shown. The art in ‘Open Window’ encourages the viewer to think about and engage in what they see from their own personal frame of reference. The artist and theorist, Duchamp (1957, 3) described this process as the viewer “bringing the work in contact with the external world by deciphering and interpreting its inner qualification”. These

principles give patients who wish to use 'Open Window' the opportunity to become part of the creative process regardless of their past experience or knowledge of art. Patients may benefit because 'Open Window' becomes whatever they want it to be and helps them deal with their physical, psychological and social needs in a unique and individualised way.

Within the context of living with and adjusting to having a life threatening illness, and without making any assumptions in relation to a patient's psychological responses, the 'Open Window' Intervention has four aims. The first is to give patients a sense of connection with the outside world. The second is to provide patients with a relaxing and soothing environment. The third is to provide an opportunity and environment conducive to self-reflection and the fourth is to extend current practice available to artists working in a clinical environment and to examine this practice within the context of current art theory.

Denis Roche, curator on the 'Open Window' project, suggests that to fulfill the criteria for delivering an intervention that allows the patient to be the arbiter of their own art experience, it is necessary to consider the artwork in terms of a dialogical and a relational aesthetic (Roche et al. 2008). The artwork in 'Open Window' lies between these two aesthetic reference points, thereby encompassing socially engaged practice but is also concerned with the human relationships that it produces. Bourriaud (2002) defines relational aesthetics as "an aesthetic theory consisting in judging artworks on the basis of the inter-human relations which they represent, produce or prompt". In his essay 'Dialogical Aesthetics: A Critical Framework for Littoral Art', Grant Kester identifies the dialogical relationship as one which the conventional distinction between artist, artwork and audience is less distinctive.' The viewer gets to 'speak back' to the artist, whose reply becomes in effect 'a part of the work itself (Kester 1999, 3). Roche refers to the work of Doherty et al (2003) to describe this in-between space as artists being interested in human inter-relations and employ everyday objects and familiar procedures to encourage interaction

(relational), whilst incorporating the participants' voices into the work (dialogical), but the artist remains the editor or director of the process. Roche et al. (2008) proposes that there are two sites where the artwork is located in the 'Open Window' project, the first part is between the artist and the staff in the unit and the second is the interaction between the artist and the patients and their families.

Prior to artists being commissioned to provide images for 'Open Window', patients were asked what kind of images they would like to see. The following are an example of the responses received:

- 'I found I had no interest in watching TV and after a long period of time in isolation I just longed to see everyday things in the outside world like natural places'
- 'I would like to see home, kids, family and natural places. This would aid recovery and reduce the sense of isolation without endangering health while counts were low'.
- 'I would like to see outdoor and sea/coastal scenes with activity such as boats passing. It would be preferable to empty spaces. It would also help occupy my mind'

This feedback from patients and the literature (Kaplan and Kaplan 1989, Ulrich 1992, Bilchik 2002, Clayton and Opatow 2003) influenced the curatorial process in that 'landscape' is the prevailing theme underpinning the content of 'Open Window'.

The effect of the 'Open Window' project on patient's experience of having a stem cell transplant remains to be seen; however, when a person has a life threatening illness they need to adjust positively to many difficult and challenging experiences over a considerable period of time and often in health care contexts and environments that, although supportive, are alien in terms of a

person's previously held assumptions about the world and their place in it. Benson's (2001) theory of aesthetic absorption suggests that within such contexts and environments, through contemplation of art work and absorption, a person can retain, modify or develop a new sense of self because the content of each art work provides a medium through which a person can have new experiences, therefore develop new perspectives on life and apply this to their own situation. This is necessary for people to give meaning to their experiences of having a life threatening illness, how it affects their personal and social interactions and their overall view of life. Folkman and Greer (2000) describe this process as one that produces positive emotions and facilitates a sustained positive adjustment to the many experiences they will have during the course of their illness.

## **2.8 Summary**

The importance of the role of art and design in providing healing and patient-centred environments appears to be well recognized. The incorporation of art and design in the planning and development stages can result in health care environments that are warm, welcoming and stimulating. Although closely related concepts, art and design are quite distinct and the presence of art, in particular, appears to have the potential to help patients in a more individualised way. It is thought to provide a medium through which patients can find comfort and retain their sense of self and self esteem in health care environments that are alien and when they are feeling anxious about their illness. This may help patients to adjust positively to the many difficult and challenging experiences they will have in the hospital environment during the course of their treatment.

Attempts have been made to test this view; however, the evidence primarily relates to the role of design in healthcare settings. Some evidence exists in relation to the positive impact of art in the health care environment but the findings from these studies are questionable due to control and sample size issues. Discussions relating to art content and theory in relation to its role in health care are also somewhat limited in the literature. Benson's (1993) theory

of 'aesthetic absorption' is very useful for explaining and clarifying why art is important for patients in a health care context. 'Aesthetic absorption' occurs when the observer, the art work and the environment become part of a new experience for the individual. This theory proposes that engagement with an art work is almost inevitable and facilitates the creation of many different experiences for patients in health care environments that are often unresponsive and over which they have little or no control.

This is particularly relevant for patients with a life threatening illness, especially those who are cared for in restricted isolated environments. Cancer diagnosis and treatment is an emotionally distressing and disturbing experience for most people. It affects a person's sense of self and their relationship with others and their environment. This in turn influences psychological adjustment to illness. Social cognitive and coping theories are traditionally used to explain a person's behaviour and also to develop appropriate therapies to help people adjust to their situation. These theories are relevant but have been criticised as being limiting and failing to account for the many responses a person has to experience along their illness trajectory. Also, they do not account adequately for why some people respond positively and others do not.

The SCT model of transition uses elements of these theories, and others, to explain a person's psychological response to a life threatening illness in a way that accounts for changes in the way a person views their illness and life situation, and how this influences their lives. The cultural psychology of self supports this as it also acknowledges the role that context and environment has in adjusting to new and difficult experiences. Like the SCT model of transition, a key aspect of this theory is that humans are active agents in their self-development often within environments and contexts not of their own making. This model proposes that it is a person's sense of self that provides stability in these ever changing and evolving environments.

## **2.9 Conclusion**

Art is important for patients receiving treatment for cancer because there is evidence that it enhances the environment due to its aesthetic value. It also facilitates reflection in relation to a person's sense of self and how they perceive their experiences of living with a life threatening illness. However, there is very little research that examines the value of art for patients in a hospital context and what exists is limited due to sampling and methodology issues. Rigorous research that identifies the way in which patients benefit from art and that measures the effect of art on health care outcomes such as anxiety, depression and distress is essential. This will encourage health care providers to include art in the planning and design process of health care environments and ultimately provide healing environments that are patient-centred and holistic. The evaluation of 'Open Window' as an intervention in the treatment of patients with haematological malignancies, using appropriate methodology and rigorous methods will provide evidence that will contribute to the current theory relating to the role of art in health care.

Research studies, including correlational and clinical trials that examine patients' experiences in relation to having cancer and effects of interventions appear to prioritise the measurement of certain outcomes. This is relevant and provides useful information in relation to providing treatments and developing services; however, it fails to account for the subjective and individualized way that humans respond to a diagnosis and treatment for cancer. The experience of having a life threatening illness disrupts and challenges a person's sense of self and everything they believed and valued in life. Psychological adjustment that results in reconstructing the sense of self and meaning to their experience is essential to prevent or limit adjustment disorders. The implications are that evidenced from primarily quantitative studies used to plan individualized care and develop services may be flawed, thus preventing optimal effectiveness. In order to provide services for cancer patients that are designed to help them psychologically adjust to their experiences of illness, it is necessary to examine

the components of positive psychological adjustment from a subjective or individual perspective.

The use of a randomized control trial design incorporating qualitative and quantitative methods for data collection will result in a rigorous study that provides evidence of the effect of the 'Open Window' and also provide information about the meaning of the patients' experience from a holistic perspective.



## **Chapter 3: Quality of Life Issues**

### **3.1 Introduction**

A diagnosis of cancer is usually associated with debilitating treatment and premature death. However, due to medical advancements, increasing numbers of patients are surviving treatment and many remain free from cancer for the rest of their lives. Consideration of quality-of-life issues for these patients is a fundamental part of helping people through their experience of diagnosis, treatment and surviving cancer or living as well as they possibly can until the moment they die. This chapter reviews the concept of quality of life from an individual and health related perspective and as a measure of outcome in cancer studies. Issues related to assessing and measuring quality of life are discussed in terms of how effective questionnaires and visual analogue scales are at providing balanced and meaningful data.

### **3.2 Quality of Life**

The concept of quality of life is complex, dynamic and subjective, therefore, it is difficult to attribute a single definition. Studies generally describe it as multidimensional, comprising individuals' perceived physical, psychosocial and emotional functioning (Dunn et al. 2003, Dunn et al. 2006). People tend to describe a good quality of life in terms of happiness, contentment or fulfilment. Aristotle suggested that mankind holds various views on what happiness is and "often the same person actually changes his opinion. When he falls ill, he says that it is his health, and when he is hard up he says that it is money" (cited in Mollasiotis 1997, p573). When considering the concept of quality of life in terms of cancer diagnosis, treatment and research, Caplan (1987) provides a framework that identifies three key aspects. The first is the physical aspect, which includes physical symptoms, response to treatment, body image and mobility. The second is the psycho-social aspect and this includes psychological responses to cancer diagnosis and treatment, interpersonal relationships,

happiness, and spiritual and financial issues. The third aspect refers to a person's individual perception of quality of life. This is influenced by their culture, philosophy, politics and the particular context or time in which it occurs. These three aspects of quality of life are considered as separate but interrelated constructs of quality of life.

In research studies related to cancer treatment and diagnosis, quality of life is generally classified as either health-related quality of life (HRQoL) or individual quality of life (IQoL). HRQoL is described as the extent to which a person's usual expected physical, emotional and social well-being are affected by an illness and/or treatment (Cella 1998). IQoL is a much broader term that encompasses all aspects of a person's life that they perceive influences their quality of life (Bowling 2005). The beliefs held by researchers concerned with assessing and measuring quality of life have clearly influenced how questionnaires have been developed and are being used either as a screening instrument or to measure effect in intervention studies. However the quality of the information produced by these instruments needs to be considered in order to be able to determine their ability to provide useful information.

Over the past 15 years, HRQoL has become recognised as an important outcome in the assessment and treatment of patients undergoing treatment for many different types of cancer. This is because the incidence and burden due to morbidity and mortality of cancer grows worldwide each year. The majority of cancer patients experience physical, psychosocial and emotional symptoms at one or more stages throughout their illness. Brorsson et al. (1993) describe HRQoL as a patient's self-assessment of their ability to conduct normal daily activities and a personal evaluation of individual health and personal situation. However, some of the instruments used to assess HRQoL have been criticised because they do not take into account the subjective and dynamic nature of perceived quality of life by individuals and tend to focus on limitations and impediments, rather than on the positive and varied factors that contribute to

quality of life (Moons et al. 2004). Individual quality of life (IQoL) instruments are based on the belief that the patient is the only person who can identify domains that determine their personal quality of life and how these domains are affected by illness or disability (Hickey et al. 1996). Some researchers believe that an individualised approach to assessment of quality of life is preferable to the use of standard questionnaires (Hickey et al. 1996, Montgomery et al. 2002).

It is apparent, however, that researchers regard quality of life as a multidimensional concept. This is reflected in the many studies that use a combination of instruments that assess physical, psychological and social well-being as separate and distinct aspects of quality of life (Montgomery et al. 2002, Moons et al. 2004, Lee et al. 2005). However, there is an assumption within this methodology that the subjective or individual dimension to quality of life is captured in the data collected even though many of the instruments used comprise predetermined quality of life indices that are identified by researchers as the relevant outcomes of care. Hayry (1999) also makes this point and suggests that in addition to these assumptions, the findings in relation to particular sample groups are often generalized to the larger population when it is not appropriate to do so. Although this is a valid criticism, studies by Bowling and Windsor (2001) and Bowling et al. (2003) suggest that the issues that people feel have the greatest influence on their quality of life are varied but yet are common to most. These include positive psychological well-being, good physical and mental health, good social and personal relationships, money and independence. These studies were conducted using an older population, therefore, applicability of these findings to other age groups is questionable. However, if one considers that perhaps the individuality lies not necessarily in the dimensions themselves but rather in how a person prioritises their influence on the quality of life in different contexts and situations throughout their lives; then it is possible that these findings are relevant across all age groups. This is evident in studies where people with life threatening illness report positive developments in their quality of life even though they are experiencing high

levels of morbidity or terminal illness (Luoma and Hakamies-Blomqvist 2004). The key factor for researchers is identifying the various constructs of quality of life and ensuring that patients do the prioritizing.

### **3.3 Quality of Life in Patients Undergoing Stem Cell Transplantation**

Diagnosis of cancer and its treatment is associated with high levels of distress which is regarded as a reliable risk for adversely affecting a person's sense of well-being (Zabora et al. 1997, 2001); however, fewer than 10% of oncology patients receive psychosocial therapy (Lee et al. 2005). The National Comprehensive Cancer Network (NCCN) defines psychological distress as 'an unpleasant experience of an emotional, psychological, social or spiritual nature that interferes with the ability to cope with cancer treatment' (NCCN 2003, p.5). Distress includes feelings such as powerlessness, sadness, fear/panic, depression and anxiety. These feelings can influence sleep patterns and interest in other areas of life and can, therefore, adversely affect quality of life. Interestingly, quality of life assessment does not correlate with physical morbidity in isolation but is also associated with emotional subscales such as anxiety and depression (Zittoun et al. 1999, Frick et al. 2004). This is particularly true of patients with haematological malignancies where studies have found that anxiety and depression are key risk factors of diminished quality of life and represent the most common emotional response (Molassiotis 1996, Sellick and Crooks 1999, Kelly et al. 2002, Montgomery et al. 2002).

Diagnosis of a haematological malignancy such as leukaemia usually necessitates immediate admission to a specialist haematology unit for intensive treatments that are aggressive, extremely disabling, result in an increased risk of infection, require prolonged periods in isolation and have a persistent level of uncertainty in terms of patient reaction and overall success (Feigin et al. 2000). Stem cell transplantation (SCT) or bone marrow transplantation (BMT) is one of the main treatments for haematological malignancies and although in the early stages of development as a possible treatment, it has also been used as a treatment for

certain types of solid tumours, for example some breast tumours (Zittoun et al. 1999, Feigin et al. 2000). Transplantations are classified as either autologous (patient's own stem cells or bone marrow) or allogeneic (stem cells or bone marrow are donated by a related or unrelated person). Generally, autologous transplantations are thought to carry less risk and have less impact on quality of life than allogeneic transplants, but the chances of relapse are greater (Prieto et al. 2005). This is reflected in the many studies that do not mix these patient groups and assess quality of life in patients undergoing autologous SCTs separately (Wettergren et al. 1997, Winer et al. 1999, Feigin et al. 2000, Frick et al. 2004, Sherman et al. 2004) to patients undergoing allogeneic SCT (Johnson Vickberg et al. 2001, Edman et al. 2001, Harder et al. 2002, Kiss et al. 2002). However, many studies do not differentiate between patient groups when recruiting participants but compare the findings between them (Molassiotis et al. 1995, Molassiotis 1999, Zittoun et al. 1999, Lee et al. 2001, Prieto et al. 2005). The findings of these studies agree that, although statistical differences occur between these groups in terms of physical and psychological experiences, over one year these differences evened out in relation to overall quality of life and psychological adjustment. Neitzert (1998) concluded from a review of literature conducted to explore various quality of life issues of patients during recovery from transplantation that these samples should not be mixed due to the substantial differences in treatments and associated distinctive physical and/or emotional side effects. It is clear that inclusion of participants undergoing autologous and allogeneic SCT or BMT does not result in a homogenous sample. Zittoun et al. (1999) warn that unless from large, randomized studies with homogenous groups of patients, findings are questionable and firm conclusions cannot be drawn. This is particularly relevant to randomized controlled trials that are conducted to determine the effectiveness of treatment interventions. If patients have different physical and psychological experiences during the course of their transplant and recovery, then it is likely that they may respond differently to psychological interventions.

### **3.4 Measuring Levels of Anxiety, Depression and Distress**

Questionnaires are used commonly to evaluate HRQoL. Many of these questionnaires comprise a list of predetermined questions relating to various aspects of quality of life, such as the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983), the Beck Depression Inventory (BDI) (Beck et al. 1996), and the European Organisation for Research and Treatment of Cancer, Quality of Life Questionnaire (EORTC-QLQ-C30) (The EuroQoL Group 1990). Although reliable and widely used in this population, these questionnaires have been criticised because the content may not be relevant to a person's individual life (Hickey et al. 1996). Also, they do not take account of the dynamic nature of quality of life issues and the documented difficulties associated with measuring quality of life. Instruments devised for measuring individual quality of life do not comprise lists of predetermined questions. Instead, the patient is asked to determine the factors that they regard as relevant and influential in maintaining their quality of life; for example, the Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW) (O'Boyle et al. 1995) the Patient Generated Index (PGI) (Ruta et al. 1994) and Spitzer's Uniscale (Spitzer et al. 1981). Whilst IQoL instruments are more subjective and reflect individual quality of life determinants, there is an underlying assumption, as mentioned earlier in this chapter, that the outcomes of both HRQoL and IQoL questionnaires can be generalized to the relevant wider population (Hayry 1999, Norman 2003). Grann and Grann (2005) go as far as suggesting that quality of life may be a more appropriate primary outcome than survival in studies that include patients with life threatening or terminal disease. The challenge for researchers is to measure and assess quality of life as an outcome in the development of physical and psychological treatments in a way that is individualized and meaningful. Otherwise the effectiveness and appropriateness of such interventions is questionable.

This is particularly relevant in comparative clinical trials in cancer treatment in which quality of life is increasingly being used as a measure of outcome (Morris

and Coyle 1994). Furthermore the U.S. Food and Drug Administration now recognises the benefits to HRQoL as a basis for approval of new anticancer drugs (Bottomley 2002) and this heightens the need for researchers to include quality of life assessment in clinical trials. The difficulty for the researcher is how to achieve this in a way that demonstrates an understanding of the unique determinants of quality of life as identified by individual patients and the meaning they attribute to these as well as identifying generic outcomes related to quality of life. It is possible for researchers to demonstrate this understanding by documenting their beliefs in relation to quality of life and how this influenced their choice of instruments. This is not common practice in most cancer studies that use constructs of quality of life as outcomes, for example anxiety, depression and distress.

Two of the most common formats for assessing health related and individual quality of life are questionnaires consisting of set determinants of quality of life with descriptive choices (mild, moderate or severe) and visual analogue scales consisting of single or multi items. Measurement tools that focus specifically on anxiety and depression as predetermined aspects of quality of life, such as the HADS and the BDI, are frequently used when assessing quality of life in patients and are among the most commonly used instruments for assessing quality of life in patients with haematological malignancies.

#### 3.4.1 Multi-Item Instruments

The HADS is a patient self-assessment questionnaire designed for physically ill patients (Machin and Fayers 1998). It consists of 2 subscales containing 7 items each. Using a one-week timeframe, the patient rates each item on a four-point scale (0-3). This questionnaire is regarded as a valid and reliable measurement tool for both anxiety and depression as separate aspects of psychological well-being. An important requirement of instruments that assess quality of life is the ability to measure changes in quality of life over time. The HADS, which is very

widely used with patients with cancer and haematological malignancies, is known to have this ability (Montgomery et al. 2002, Katz et al. 2003).

The Beck Depression Inventory (BDI) (Beck et al. 1996) was specifically designed as a tool to measure severity of depression. It is a self-administered instrument consisting of 21 items, each of which is accompanied by four statements about the symptom of depression. The statements are rank ordered and weighted. Numerical values of 0, 1, 2, 3 are assigned to each statement to reflect the degree of severity experienced by the patient. Although used more frequently in mental health populations, this tool is reported to have moderate to high levels of validity and reliability even in cancer patients (Miranda et al. 2002, Katz et al. 2003, Love et al. 2004). The latest version of the BDI is BDI-Fast Screen (for medical patients) which is a 7-item self-report measure of depression. This version is now the recommended Beck inventory for cancer patients as it removes many of the somatic type items that overlap with physical illness for example, fatigue and appetite and weight loss (Beck et al. 2000).

An instrument devised specifically for assessing quality of life in cancer patients by the European Organisation for Research and Treatment of Cancer (EORTC) is the EORTC QLQ-C30 (The EuroQoL Group 1990). This is a health-status focused quality of life questionnaire comprising 30 items grouped into nine symptom scales and six functional scales. A number of modules related to specific illness, such as head and neck, lung and breast cancer, have been developed for this tool and are included with the core questionnaire (Wisloff et al. 1996, Zittoun et al. 1999, DeHaes et al. 2000). This instrument is frequently used to assess quality of life either as the sole instrument (Hayden et al. 2004) or in conjunction with tools such as the HADS, BDI and SIEQoL-DW in patients with cancer and haematological malignancies (Wettergren et al. 1997, Keogh et al. 1998, Zittoun et al. 1999, Frick et al. 2004).



Instruments commonly used for measuring IQoL in patients with haematological malignancies include the SEIQoL-DW (O'Boyle et al. 1995) the Patient Generated Index (Ruta et al. 1994) and Spitzer's Uniscale (Spitzer et al. 1981). The Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW) is based on the belief that the determinants of quality of life can only be identified by individuals (Montgomery et al. 2002). This is a researcher-administered questionnaire that takes approximately 30 minutes to complete and has been used across a range of clinical applications (Hickey et al. 1996, Waldron et al. 1999, Frick et al. 2004). The use of this instrument comprises 3 stages. Firstly, patients are asked to list the main five aspects of their life that influence their overall quality of life. Secondly, they are asked to rate the current level of each of these determinants on the vertical axis of a visual analogue scale with a score range of 0-100. Thirdly, they are asked to weight the importance of each of the five determinants individually out of a total score of 100. This is a useful tool because it acknowledges the subjective and dynamic nature of quality of life issues for patients. The SEIQoL-DW instrument produces a global quality of life score and a current overall score that is rated on a Visual Analogue Scale. It is widely used in assessing quality of life in cancer patients, although it is not commonly used in clinical trials; this may be because it is researcher-administered and is time consuming.

A study by Frick et al. (2004) on individual quality of life of patients undergoing autologous peripheral blood stem cell transplantation found no correlation between the scores for this tool and the EORTC QLQ-C30 scale. They concluded that patient-perceived quality of life in this patient group depended primarily on aspects of life unrelated to health and physical functioning, and identified that family and social interaction were more important. This conclusion is supported by Moons et al. (2004) and Sloan et al. (1998) who found that patients report more of the psychosocial aspects of the quality of life construct whereas physicians focus primarily on variables related to physical functioning. Another possible reason why this instrument is not used in clinical

trials is that, as it is widely known that anxiety and depression are two key factors that adversely affect quality of life in this patient group, tools that focus on measuring these subscales in particular are more relevant and informative in terms of identifying changes in as a result of a treatment or intervention in clinical trials or as a screening tool in providing individualised patient care or developing patient services.

#### 3.4.2 Visual Analogue Scales

Sloan (2002) suggests that in an effort to ensure validity of quality of life measurement tools, clinical trials are becoming increasingly complex and that information needs can alternatively be met by asking single item questions rather than by using multi-item, multidimensional, psychometrically sound, valid and reliable instruments. Bech (1999) describes visual analogue scales as useful in facilitating the quantification of open responses because they facilitate the assessment of single or multiple dimensions of global quality of life.

The visual analogue scale (VAS) is regarded as a more valid reflection of attitudes, feelings and how an intervention or course of illness can affect individuals than the Likert scale (Pfenning et al. 1999). It can be used to measure aspects that are important to quality of life, for example, pain (Schwenk et al. 2002), mood (Bernard et al. 2001) distress (Jacobsen et al. 2005) and global quality of life (Sloan et al. 1998). VASs generally consist of ordinal data with a discrete or continuous range of possible values. They consist of a line (usually 10cm in length), presented either horizontally or vertically, which is anchored at either end by extremes of the measured variable. VASs can be either unipolar or bipolar. Unipolar scales rate the intensity of a phenomenon such as appetite between the extremes of the phenomenon, ('None' - 'Excellent'). Bipolar scales are used to measure mood labels denoting extremities of the mood at either end of the line, for example, 'no distress' and 'extreme distress' (Trask et al. 2002). Examples of VASs are the Linear Analogue Self-Assessment (LASA) (Priestman and Baum 1976) and Spitzer's Quality of Life Index (QL Index) (Spitzer et al.

1981). These examples of VASs comprise a list of predetermined questions related to aspects of quality of life. De Boer (2004) found it to be as valid, reliable and responsive over time as other multi-item scales.

In contrast, the Patient Generated Index (PGI) (Ruta et al. 1994) is a visual analogue scale that was developed as an individualised measure of quality of life in which the respondents identify 5 of the most important areas of their life. The concept underpinning this scale is similar to the SIEQoL-DW. The participants are then asked to rate how badly affected each of these areas is by their illness. Finally, they are asked to identify which aspect of their lives they would like to improve the most if they could. Although a simple tool, the PGI is reported as being unsuitable for self- or postal administration because it can be a complex process for those unfamiliar with the underlying concept (Bowling 2005).

Spitzer et al's (1981) Uniscale, although originally designed as part of a quality of life index, is often used on its own as a means of assessing patient perceived overall quality of life. Patients are asked to place an X on a horizontal line that indicates their quality of life over the past week that is anchored at one end by 'lowest quality of life' and the other as 'highest quality of life'. It is reported as a valid and reliable tool for measuring overall quality of life and as being more sensitive to change than multi-item instruments (Hopwood et al. 1994, Cella 1996, Sloan et al. 1998).

Distress related to the diagnosis and treatment of cancer is often misjudged by doctors (Roth et al. 1998, Holland 1999). Failure to identify and deal with distress reduces quality of life generally and can result in non-adherence to treatment, low self esteem and negative feelings (Gammon 1998, Trask et al. 2002). The 'Distress Thermometer', a VAS that is becoming increasingly popular in assessing psychological well-being in cancer patients, is an individualised single-item VAS developed by Roth et al. (1998) as a rapid screening tool for distress in cancer patients. Patients rate their perceived level

of distress using a scale ranging from 0 ('no distress') to 10 ('extreme distress'). A study by Trask et al. (2002) found that although the distress thermometer was effective in measuring levels of distress and was sensitive to changes in levels of distress over time, it was not able to provide detail relating to the causes of distress in patients with haematological malignancies. Since this study, the 'Distress Thermometer' (DT) has been adapted to include a problem list that patients use to identify issues that have caused them distress in the last week (NCCN 2003, Figure 1). The list includes 34 issues that are grouped into 6 categories: Practical, Physical, Family, Emotional, Other Problems and Spiritual/Religious concerns. Patients are asked to tick YES or NO to the items listed as being a problem in the past week. The results of a study by Jacobsen et al. (2005), conducted since the incorporation of the problem list, identified a combination of practical, emotional and physical issues as the main factors causing distress in patients with cancer. Although a relatively new instrument, the distress thermometer has been used in a number of studies involving patients with cancer (Roth et al. 1998, Akizuki et al. 2003, Hoffman et al. 2004, Jacobsen et al. 2005, Akizuki et al. 2005) and haematological malignancies (Trask et al. 2002, Lee et al. 2005). The results of these studies suggest that the 'Distress Thermometer' is a valid and reliable tool for screening cancer patients for distress and it correlates well with the HADS.

A number of studies report a cut-off score of  $\geq 5$  as having optimal sensitivity and specificity for identifying distress (Roth et al. 1998, Trask et al. 2002) and this is also recommended by the NCCN who devised the instrument. However, following receiver operating characteristic (ROC) curve analysis, studies by Jacobsen et al. (2005) and Patrick-Miller et al. (2004) report optimal sensitivity and specificity occurring at a cut-off score of  $\geq 4$ . This contradicts the findings of a study by Hoffman et al. (2004) that also used ROC curve analysis and found that no single cut-off score provided optimal sensitivity and specificity. The population for all three studies was ambulatory cancer patients, and the reason for the different result possibly lies in the sample size. Jacobsen et al.'s (2005)

study had a sample of 380 and Patrick-Miller et al's (2004) study had a sample of 1,271. The sample for Hoffman et al's study was only 72, possibly too small to detect optimal values (Jacobsen et al. 2005). This instrument appears to be a patient-centred and easy to use individualised quality of life measurement instrument that is effective in detecting cases of distress and is sensitive to changes in levels of patient distress over time. This is an essential requirement when assessing quality of life in patients with haematological malignancies, particularly when undergoing a stem cell or bone marrow transplant.

Patrick-Miller (2004) makes the observation that, when compared to the criterion measures of the HADS (HADS-Total, HADS-Anxiety, HADS-Depression) the DT is better at detecting global distress and anxiety than depression. The problem here is that although distress and anxiety are more prevalent in this patient group than depression, the occurrence of depression is very clinically significant. This raises the question of whether or not the DT should always be used in conjunction with the HADS. As the HADS is already well established as being very effective in detecting anxiety and depression separately, it may be sufficient to use on its own when assessing this aspect of quality of life in cancer patients and patients with haematological malignancies.

Visual Analogue Scales are not, however, used frequently in studies related to quality of life issues. This may be due to a number of disadvantages associated with VASs. The first of these is that scoring in VASs can result in a tri-modal distribution of scores; that is, the respondents may only view the scale as having the options of low, medium and high instead of viewing it as a continuum (Revicki and Kline Leidy 1998). The scoring on VASs is somewhat arbitrary, making the interpretation of group differences and changes questionable (Revicki and Kline Leidy 1998, Svensson 2000). Svensson's (2000) study found large individual variability in the scoring on a VAS in relation to pain, thus demonstrating the non-linear properties of VASs. She suggested that equidistant rescaling of VAS assessments resulted in an inter-scale bias when VAS

responses were grouped into discrete scales. She concludes that the VAS is not a reliable tool for clinical research and that the choice of treatment or classification of severity for an individual should not be based on the interpretation of VAS responses derived from group studies (Svensson 2000). However, Grunberg et al. (1996) argue that the linearity of visual analogue scales can be questioned (because an initial evaluation of a symptom at or near the extreme score of a VAS may preclude a linear trend of improvement or deterioration with continuous measurement), and cannot be ensured even on initial evaluation of a particular symptom. They propose that education, training and assistance for respondents to complete visual analogue scales accurately is essential. This is particularly relevant for patients with haematological malignancies that have poor functional ability, particularly when undergoing a bone marrow transplant.

In Grunberg et al's (1996) study one of the most interesting findings was that the respondents did not make a clear distinction between the terms 'mildly' and 'moderately' whereas the term 'severely' had a distinct range of values and suggests that assignment of numerical values may rectify this, although it is possible that researcher assistance and clarification could have the same effect. Grunberg et al. (1996) acknowledge that VAS may not have the validity of a detailed questionnaire and their study does not define sensitivity or reliability of small changes on a VAS to true changes in symptoms. However, they question whether such minor distinctions have significant meaning. Grunberg et al. (1996) conclude that the use of a VAS alone is not appropriate for measuring quality of life but, when used with other measuring tools such as the HADs or EORTC, the ability to correlate and compare values obtained from verbal data, numerical data and VAS will facilitate the evaluation of the different factors relevant to individual and health related quality of life. Many studies (Sloan et al. 1998, Bernhard et al. 2002, Akizuki et al. 2003, DeBoer et al. 2004, Lee et al. 2005) have used a VAS with a multi-item questionnaire and found moderate to high correlation; therefore, it is probably reasonable to suggest that minor distinctions are not significant.

In order to encourage oncologists and haematologists to include single item instruments when assessing individual or health related quality of life, Sloan (2002) highlights the need for a consensus on assessing the clinical significance of such simple global QOL outcomes, and suggests that Cella et al.'s (2002) trichotomy of effect (improved, unchanged, worsened) is useful and appropriate when classifying patient response and interpreting quality of life scores in clinical trials.

### **3.5 Issues in interpreting data derived from quality of life measurement**

Guyatt et al. (2002) also acknowledge the difficulties associated with interpreting quality of life research findings derived from visual analogue scales and multi-item questionnaires into distinguishable differences between statistical significance versus clinical significance; that is, findings that are clinically meaningful. Svensson (2000) made a similar point that inferences cannot be made between inter-individual scores or group scores because of the lack of detail in relation to descriptions of the dimension being studied and the scores. Osoba (1999) suggests that although small changes in quality of life scores can be statistically significant, these changes may not be meaningful to either a patient or doctor. It is also possible that by assuming that individual scores represent the mean effect of a treatment, clinical decisions based on summarising the effect of a treatment as a difference in means is flawed. Cella et al. (2002) suggest that when interpreting data from quality of life measurement instruments, in order to develop an accurate set of individual classifications across a group of patients, the use of group-derived individual cut-off scores for change is an acceptable practice. Assignment of individuals within a group to 1 of 3 categories (improved, unchanged, worsened) facilitates the classification of individuals in clinical trials in terms of how many people benefited or worsened as a result of the treatment under certain conditions. They acknowledge that although this group data can be used to discuss and make statements about individual changes, there will be some measurement error.

Explaining the clinical significance of quality of life measures can be expressed in terms of between-person standard deviation units, within-person standard deviation units and the standard error of measurement. Guyatt et al. (2002) suggest that no one approach to interpreting data is perfect and proposes the use of multiple strategies to enhance the interpretability of any particular instrument, including using a number of measurement instruments. This is evident from the number of studies that have used a visual analogue scale in conjunction with other instruments such as the HADS or Beck Depression Inventory- Fast Screen (Montgomery et al. 2002, Hoffman et al. 2004, Lee et al. 2004). Sloan (2002) says that issues related to validity, reliability and clinical significance prevent the use of quality of life instruments by clinical oncologists in assessing outcomes of care. This has implications for meeting the psychological needs of patients with haematological malignancies and has further implications when the results of studies by Stephens et al. (1997), Sloan et al. (1998) and Titzer et al. (2001) are considered. These studies found that oncologists frequently under-reported symptom severity and health-related quality of life when compared with patient-rated symptom severity and quality of life. Doctors tend to focus on physical symptoms when assessing quality of life whereas patients regard psychological status and well-being as the primary influence on quality of life. The use of HRQoL instruments and IQoL instruments to provide clinical interventions that are appropriate, effective and patient-centred, appears to be essential. It is worth noting, however, that although quantitative studies can identify and assess quality of life issues that are either pre-determined, as in some instruments, or are identified and assessed by individuals, normative data are not meaningful when applied to individual lives (Xuereb and Dunlop 2003). Using a combination of quantitative and qualitative methods for data collection, even in clinical trials, would alleviate this problem.

A study by Chochinov et al. (1997) compared the performance of four brief screening measures for depression in a group of terminally ill patients. The methods used were the BDI-short form, a visual analogue scale for depressed



mood and two structured interviews. The findings indicated that interviews comprising direct questions were more valid than the questionnaires. This does not negate the relevance or importance of health related and individual quality of life instruments; however, it serves to highlight that such instruments are useful but their inclusion in any study ultimately depends on its purpose. Hyland (1999) suggests that when included in clinical trials, quality of life is perceived and assessed separately to morbidity and mortality rates when in fact they are closely related. This does not necessarily mean that patients experiencing greater physical discomfort, pain and other changes automatically have a reduced quality of life; what is important to patients is how these affect their social roles and personal sense of self. It is probably more appropriate to suggest that both quantitative and qualitative approaches to quality of life assessment as an outcome are appropriate and produce a more comprehensive, individualised and holistic type of data that can be presented in numerical and written format. Qualitative data resulting from either structured or unstructured interviews would not only add meaning to the individual scores of patients but would strengthen and complement the overall study scores. The use of mixed methods provides an opportunity to reach an understanding of complex, multifaceted and individual realities (Tashakkori and Teddlie 2003). However, the literature provides evidence that studies relating to patients' experiences of having cancer and responses to cancer treatment rarely give attention to subjective data (Zebrack 2000, Dunn et al. 2006). Norman (2003) suggests that standardised instruments, while useful in interpreting the results of clinical trials, are not so valuable in determining the needs and treatment required by individual patients. He acknowledges the importance of using mixed methods in studies concerning quality of life in order to understand its meaning and how it influences patients' experiences and responses to illness. This view is supported by McCabe et al. (2007) who conclude that the use of semi-structured interviews with questionnaires in clinical trials can provide clarity, understanding and meaning of the effect of new treatments for patients and health care staff. For example, it appears from the literature discussed so far, that a balance between the treatment

for physical and psychological needs perhaps needs more emphasis in the planning and development of oncology/haematology services.

Using quantitative approaches solely in cancer research related to quality of life for these patients, and also in clinical trials, does not reflect the abstract and complex nature of the concept of quality of life and the influence of individual experiences and expectations (Molassiotis 1997). As discussed in chapter 1, to ignore the meaning that an individual attributes to their illness and treatment is to lose the essence of their individuality in the context of having a life threatening illness. By implication, the ability of any health care service to provide individualised or patient-centered care is greatly limited if it must rely on one-sided evidence to plan and develop services.

### 3.5.1 Qualitative Issues relating to Quality of Life Research

A qualitative study by Luoma and Hakamies-Blomqvist (2004) demonstrates this point. The purpose of their study was to investigate the meaning of advanced breast cancer patient's quality of life. Data were collected from twenty five women who had experienced two or three courses of chemotherapy using semi-structured interviews. The findings of this study suggest that patients regard their physical and psychological well-being as interrelated in terms of affecting their quality of life. The ability to control their illness experience emerged as a key factor in maintaining a positive quality of life. What is particularly interesting about this study is that it was conducted in parallel with a randomised control trial using the EORTC QLQ-C30. The women who participated in Luoma and Hakamies-Blomqvist's (2004) study were also randomised to a clinical trial and who received either Methotrexate-Fluorouracil (M-F) or docataxel. The side effects of M-F were more nausea and vomiting than docataxel, which caused alopecia, fluid retention and neuropathy. A secondary purpose of Luoma and Hakamies-Blomqvist's study was to determine the subjective and individual issues that affected the quality of life of these cancer patients that were not

identified by the EORTC QLQ-C30. They concluded that key issues that affected quality of life such as increasing dependency on others and isolation due to changes in appearance and lifestyle that emerged from both groups could not have been detected by the EORTC QLQ-C30. They recommend that the use of standard quality of life instruments in research should be supplemented with interviews in order to provide clarity and a theoretical basis for findings. Larsson et al. (2003) reported similar findings in their study that explored distress, quality of life and strategies to 'keep a good mood' in patients with carcinoid tumours. Using a combination of questionnaires (EORTC QLQ-C30 and HADS) and semi-structured interviews with 19 patients and 19 staff, they found that distress was generally caused by physical problems and perceived quality of life was influenced mainly by social issues. They also concluded that many aspects of emotional distress were identified through the interviews that could not have been determined by the questionnaires. These included issues related to worrying about the future, troublesome tests/examinations and adverse effects on their social interactions and roles.

The implications of this are that medical and nursing staff are not fully aware of the issues that affect a person's sense of self and well-being and therefore, may not be successful in helping patients adjust to having a life threatening illness. A mixed methods study by Persson et al. (2001) that investigated the quality of life of patients with acute leukaemia and malignant lymphoma over a two year period, also reported that data from personal interviews should be compared with responses given in standardised quality of life questionnaires before any assumptions about clinical relevance can be made. These findings are supported by Keogh et al. (1998), who used a prospective, repeated measures and mixed methods design to investigate the psychosocial functioning of patients and close relatives pre- and post-allogeneic and autologous bone marrow transplantation. They used the data from the qualitative interviews with the quantitative outcome data to produce a more complete and meaningful presentation of the findings.

Overall there is a dearth of qualitative research in relation to patients' experiences of having cancer. However, those studies that do exist (Taylor 1983, Luker et al. 1996, Bertero et al. 1997, Magnusson et al. 1999, Landmark et al. 2001, Ramfelt et al. 2002, Richer and Ezer 2002) share a common theme, which is the importance for patients of finding meaning in their experience of illness and its effect on them as individuals and their relationships with others. This issue perhaps is not that studies using HRQoL or IQoL instruments only for assessing quality of life in patients with cancer are limited. They fulfill their purpose by providing data about specific or general health issues that affect a person's overall quality of life in terms of having a chronic or life threatening illness. These data are relevant for intervention studies; however it reflects a narrow view of the concept of quality of life and could not elicit how important 'finding meaning' is for a person in terms of overall adjustment to having a life threatening illness and how this influences their quality of life. The influence can be positive or negative or both. This has implications for how the findings of studies that use only HRQoL instruments are used to determine clinical and statistical significant outcomes that are used to develop cancer care services.

Based on this review of the literature, it is arguable whether or not the development of standardised support packages is appropriate for all patients given the diversity in how they perceive their quality of life. However, perhaps this is not a feasible suggestion given the economic constraints and challenges facing health care providers. The provision of standardised support packages is important in allowing health care managers to plan budgets and manage resources but they need to provide packages that are comprehensive. This means including access to psychological and social support structures for patients when they feel it will enhance their quality of life. A patient-centered approach to health care planning and development is needed for this to be a reality and this can only happen if the evidence from clinical trials and exploratory studies is

patient-centered. Danaher Hacker (2003) suggests that issues such as the purpose of the study, the conceptual approach, patient burden and available resources are the primary concerns in choosing appropriate methods. The plethora of studies using primarily HRQoL and IQoL instruments to assess quality of life suggests that perhaps researchers are only paying lip service to the centrality of dynamism and subjectivity to this concept. McMurtry and Bultz (2005) refer to this as the gap that exists between biomedicine and psychosocial reality.

### **3.6 Summary**

Quality of life is a dynamic concept that is individually constructed and assessed by human beings. In cancer studies, HRQoL and IQoL instruments are used to measure quality of life. Anxiety, depression and distress are documented as the key risk factors of diminished quality of life in patients with haematological malignancies. HRQoL instruments such as the HADS and Distress Thermometer are generally used to measure these outcomes. Although regarded as valid and reliable instruments, they are also criticised because they do not reflect the individual aspects of quality of life. IQoL instruments such as the SEIQoL-DW and the patient generated index reflect the individual nature of quality of life and allow patients to identify and weight their own constructs of quality of life. These outcomes are measured using questionnaires or visual analogue scales, both of which the literature suggests are valid in measuring quality of life.

The literature suggests that, prior to commencing a study and choosing the appropriate instruments, researchers should determine how the findings are interpreted in terms of clinical and statistical significance. Inferences made by researchers and clinicians between inter-individual and group scores are also questionable. One suggestion to overcome this is the use of group derived individual cut-off scores for change in order to produce an accurate set of individual classifications across a group of patients. Due to patient burden,

instruments used to measure quality of life in patients with haematological malignancies need to be easy-to-use and not time consuming.

Quality of life and morbidity and mortality rates are often perceived and assessed separately. However, they are closely linked because experiences such as physical discomfort and pain adversely affect quality of life due to the way in which they change or eliminate normal social roles and personal sense of self. The use of quantitative and qualitative approaches may produce more comprehensive, individualised and holistic data when measuring and assessing quality of life. The few qualitative studies that explore quality of life in cancer patients indicate that mixed methods of data collection will facilitate a greater understanding and meaning of quality of life and how it influences patients' experiences and responses to illness.

### **3.7 Conclusion**

Diagnosis of a haematological malignancy is both physiologically and psychologically distressing. The physical trauma and resulting distress is well recognised and it is often prioritised as the main determinant of quality of life by doctors. However, patients, especially those with haematological malignancies, consider psychological factors such as emotional distress, anxiety and depression as the key determinants of quality of life.

HRQoL questionnaires such as the HADS, BDI and EORTC are criticised because although they are reliable, the content may not be relevant to individual patients' experiences as they are unable to elicit subjective data relevant to all. These instruments do not consider the individualised and dynamic nature of quality of life for patients. Individual quality of life instruments such as the SEIQoL,-DW, PGI and Uniscales are based on the premise that quality of life determinants are unique to individuals, and therefore should not be pre-determined by researchers. HRQoL and IQoL instruments are comprised most commonly of questionnaires or visual analogue scales.

VASs are regarded as effective instruments because they are quick and easy to use and reduce the burden on the patient. However VASs have been criticised for resulting in a tri-modal of scores, thus making the interpretation of group and individual differences and changes questionable. Detailed explanation and education by the researcher could overcome this although this implies that VASs are probably more effective and accurate if administered by the researcher.

A criticism of questionnaires and VAS's is that the findings from both do not distinguish differences between statistical and clinical significances. The use of group derived individual cut-off scores is regarded as appropriate for classifying patients in terms of how they benefited or worsened as a result of an intervention and also allows statistical significance to be calculated. It is also recommended that VASs that correlate with questionnaires should be used jointly. This is seen in a number of studies assessing quality of life in patients with cancer and haematological malignancies that use the DT and the HADS together.

The question of whether group or even individual findings from HRQoL or IQoL instruments are relevant or meaningful is an important one. It is possible to suggest that the findings are relevant in evaluating the effect of treatment interventions but are not so valuable in terms of providing data that can help health care professionals to determine the individual needs of patients. The use of mixed methods, particularly in clinical trials, is recommended as a means of providing greater meaning and understanding of the quantitative data and also identifying individual perspectives on the experience of patients in relation to quality of life issues. On this basis, the 'Open Window study was designed to include mixed methods for data collection and analysis. It is expected that the results will provide information about the possible psychological effect of 'Open Window' but will also explain participants views on it and how it may have influenced their experience of having a stem cell or bone marrow transplant.

## **Chapter 4: Study Design**

### **4.1 Introduction**

This chapter presents details of the background to the study, the research questions, and aims of the study, hypothesis to be tested and research design. Also included are details relating to the study population, sample size estimates, data collection tools, and ethical issues. This is a prospective longitudinal study using a randomised controlled trial, pre and post-test design with mixed methods for data collection and analysis. Although the design of this study is grounded in positivism, the use of mixed methods for data collection and data analysis demonstrate my belief that qualitative and quantitative paradigms are necessary in order to answer the research questions and can be integrated in meeting the aims of the study.

### **4.2 Background of the Study**

In 2001 the Director of the Denis Burkitt Unit had a chance meeting at the Irish Museum of Modern Art (IMMA) with both an ex-patient who had received a stem cell transplant 10 years previously and an ex-nurse from the unit who was now an artist in residence. Following on from the discussion that arose from this meeting and in addition to feedback from patients over the years, it became clear to the Director that the internal environment for patients undergoing stem cell transplantation lacked imagination and stimulation. Patients also complained that views from their windows included an air conditioning plant for the unit (90cms away from the window), waste ground, or an adjacent hospital building that blocked out the sun and ability to see the sky. Although purpose built, the focus of the design clearly had been on its functionality in providing treatments to patients rather than recognition that bright, airy, and visual and mentally stimulating environments are essential for patients recovering from any illness. This is compounded by restrictions for a 4-6 week period on movement and visiting enforced in order to prevent infection.



Shortly after this, an artist working with the human connectedness group in Media Lab Europe heard about the encounter. His work at that time was investigating the defining features of human interaction and how technologies could be adapted to become an integrated part of this process. As a result of reflection on his media lab project and the environmental issues raised in relation to patients in the Denis Burkitt Unit, the artist proposed the construction of a digitally generated 'virtual window,' which could be projected on the wall at the foot of the patient's bed. This 'virtual window' was conceptualised as a virtual art gallery that would be constituted with both visual and auditory artworks.

The Director of the unit was enthusiastic about this proposal and believed that art was possibly an effective medium for alleviating the clinical and unresponsive design of the rooms and also for helping patients to adjust psychologically to having a stem cell transplant as treatment for a life threatening illness and possibly surviving it. Once the concept was agreed in principle by the Director of the unit and the artist, a medical physicist employed by the hospital was introduced to the team. His purpose, in conjunction with the Director of the unit, was to act as a link between the artist, who was regarded as an external agent, and the hospital management. A second key aspect to his role was to provide expertise and guidance in terms of the technology, equipment and processes required to make the 'virtual window' a reality in the Denis Burkitt Unit. This was named the 'Open Window' Project and over the following two years a prototype was developed that met with the hospital's guidelines on infection control and patient safety. With funding from the Bone Marrow for Leukaemia Trust and other interested groups, 'Open Window' became available to patients in summer 2003. The 'Open Window' prototype was installed initially in 2 rooms in the Denis Burkitt Unit in 2003.

A main priority for the 'Open Window' Project team was to ensure the provision of artworks for the system and to evaluate its effect on patients undergoing stem

cell transplantation. Following a decision to conduct a study to evaluate the psychological effect of 'Open Window', approaches were made to the psycho-oncology services in the hospital and Professor Cecily Begley, Director of the School of Nursing and Midwifery, Trinity College to join the research team. Successful grant applications were made to the Irish Cancer Society and Vodafone Foundation Ireland to conduct the evaluation within the context of a randomised controlled trial. The Irish Cancer Society funding facilitated my employment as a research fellow and my role was to develop, conduct and lead the randomised controlled trial to measure the psychological effect of 'Open Window' and assess any potential influence it had on participants' experiences of having a stem cell or bone marrow transplant. My role included liaising with the psycho-oncology services in the Denis Burkitt Unit in relation to the most appropriate psychometric instruments to measure the psychological effect of 'Open Window'. In order to evaluate participants' views on 'Open Window' and determine whether it influenced their overall experience of having a transplant, I also developed two further instruments and the interview guide. I applied for the position of research assistant on this project because my research interests are communication and patient-centeredness and, as a nurse, I have a particular interest in treatment interventions that represent a patient-centered approach to care. This funding also provided a salary for an artist as a curator for the project. The funding from Vodafone Foundation Ireland was awarded specifically for the further development and installation of an updated 'Open Window' system in 8 rooms in the Denis Burkitt Unit in July 2005.

Although St. James's Hospital has an Arts Committee and employs an Arts Director that supports the 'Open Window' project, it exists outside its structures in terms of funding and control. The Arts Director works with the hospital Arts Committee and hospital management in introducing visual and/or performing arts in various locations around the hospital. Funding for my salary for a three period was secure, costs for conducting the trial, data inputting, transcribing of interviews and statistical advice were not available. In 2006, therefore, I

submitted an application to the Irish Cancer Society for a PhD student grant and was awarded €20,000 to cover these costs.

### **4.3 Purpose of the Study**

The purpose of this study is to measure and evaluate the effect of ‘Open Window’ on patients’ psychological well-being and experience of having a stem cell or bone marrow transplant. The primary outcome related to HRQoL and the level of anxiety, depression and distress experienced by participants over time. These were measured using the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983) and the Distress Thermometer (DT) (Roth et al. 1998). The secondary outcome was determining if participants’ experience of having a transplant met their expectations and this was measured using the expectations questionnaire designed specifically for this study.

#### **4.3.1 Research Questions**

1. Does ‘Open Window’ have an effect on a patients’ psychological well-being when undergoing stem cell or bone marrow transplant?

Aim: To test the null hypothesis that ‘Open Window’ has no effect on participants’ levels of anxiety, depression or distress over time.

Aim: To measure participants’ level of anxiety, depression and distress before, during, and after stem cell transplantation.

Aim: To conduct sub-group analysis to compare levels of anxiety, depression and between patient undergoing allogeneic and autologous stem cell or bone marrow transplants.

2. Does ‘Open Window’ influence a person’s overall experience of having a stem cell or bone marrow transplant?

Aim: To determine the type of influence, if any, that ‘Open Window’ has on participants’ experiences of stem cell or bone marrow transplantation.

Aim: To identify patients’ perspectives on the primary factors, including ‘Open Window’ if applicable, that influenced their experience.

Aim: To identify patterns in how patients used the ‘Open Window’ Technology

3. Does 'Open Window' have a long-term effect on a person's experience of having a life threatening illness?

Aim: To ascertain if participants continue to use art in any way in their lives after the experience of having a stem cell or bone marrow transplant.

#### **4.4 Hypothesis to be tested**

'Open Window' has no effect on patients' levels of anxiety, depression, or distress when undergoing a stem cell or bone marrow transplant.

#### **4.5 Study Design**

This study is a randomised controlled trial using a pre-test/post-test design and mixed methods for data collection and analysis. This experimental design is a quantitative research approach, which is grounded in the positivist paradigm. This paradigm, or philosophy as it is also referred to, originated in the natural sciences and researchers that use it to underpin and guide their research believe that knowledge is developed through systematic observation and measurement. Research designs based on this philosophy reflect the view that social and physical phenomena are equally observable and measurable and that all research should be objective. The key assumption associated with positivism as a research methodology is that knowledge is independent and objective, and can be used to explain, predict or control a phenomenon regardless of its social or cultural context (Richardson 2000, Burke Johnson and Onwuegbuzie 2004). On the basis of these beliefs, quantitative researchers conduct research in order to determine cause-and-effect relationships and generalise about a phenomenon (Knapp 1998).

##### **4.5.1 Quantitative Research Designs**

There are 4 well-recognised designs associated with quantitative research, classified as descriptive, correlation, quasi-experimental and experimental.

#### *4.5.1.1 Descriptive Research*

Descriptive research is used to generate knowledge on topics about which little is known. The purpose of this research design is to explore and describe concepts and identify relationships within or between phenomena (Burns and Grove 1997). One of the key types of descriptive research is the survey. This research approach facilitates the collection of large amounts of data in relation to the practices, opinions, attitudes and other characteristics of particular populations or groups. Knapp (1998) describes surveys as useful but superficial with careful consideration needed in relation to sampling and measurement issues; this is perhaps an issue for all research designs and not just descriptive research. Burns and Grove (2005) and Parahoo (2006) suggest that the advantage of surveys is that they can be administered to large populations, often include a wide range of topics and are used for descriptive and correlation studies. This study used a survey questionnaire in order to assess participants' views of 'Open Window' on a range of issues; for example, how it made them feel, personal preferences and when and how often they turned it on. A 31-item questionnaire was developed for this purpose and details of its development and testing are discussed in section 4.9.3.

#### *4.5.1.2 Correlational Research*

Correlational research is a design used to examine relationships between variables but does not actively manipulate the independent variable(s). The purpose of this design is to establish the type (positive or negative) and degree (strength) of the relationship, which can range from -1 (negative correlation) to +1 (positive correlation) with 0 representing no correlation or relationship (Burns and Grove 1997, Knapp 1998). Knapp (1998) classifies correlational studies as ordinary or comparative. Ordinary correlational studies are exploratory, predictive or explanatory. Comparative studies can be prospective, cross-sectional, retrospective, and include case control studies. Although some manipulation of variables may occur in these studies, causality cannot be clearly stated; however, this design is useful for conducting research in contexts where

experimentation is not feasible (Knapp 1998). This design was not appropriate for this study because the absence of control limits its ability to establish cause and effect (Polit et al. 2001).

#### *4.5.1.3 Experimental Research*

Experimental research is also used to investigate cause-and-effect relationships between dependent and independent variables; however, unlike the research designs already described, this is conducted under highly controlled conditions (Burns and Grove 1997). In order to be classified as an experiment, a research design needs to include three components: manipulation, control and randomisation. The purpose of these components is to control for extraneous variables that could threaten the internal validity of the study. Manipulation refers to the control of the independent variable and observation of its effect on the dependent variable by the researcher. An example of this in health care is the introduction of a treatment intervention (independent variable) to one group of study participants while simultaneously with-holding it from a separate group. Control in experimental research refers to controlling as many variables as possible in terms of the study context and participants and requires the inclusion of a control group in the design (Parahoo 1997, Polit et al. 2001). The control group do not receive the new treatment intervention and their response to 'standard' treatment is used as a benchmark for evaluating the response of the experimental or intervention group. The use of a control group in conjunction with an explicit and clearly defined protocol that directs the study provides assurance of high levels of consistency in implementing the independent variable and data collection.

The third essential component for an experimental research design is randomisation or more specifically, random allocation. This means that each participant has an equal chance of being assigned to the intervention or control group, thereby eliminating bias. Friedman et al. (1998) suggest that the essential feature of random allocation of participants is that it greatly increases the chances

of producing comparable groups, as confounding variables should be equally distributed, and it guarantees the validity of statistical tests of significance.

#### *4.5.1.4 Quasi-experimental Research*

Before discussing the main experimental research designs, it is helpful to briefly refer to quasi-experimental research. Quasi-experimental research designs are similar to experimental research because they include manipulation of an independent variable, i.e. the introduction of a new treatment or therapeutic intervention (Knapp 1998, Polit et al. 2001). Examples of this type of research include the non-equivalent control group and time-series designs. The non-equivalent control group pre and post design includes the use of a control group but not random allocation. The time-series design has neither a control group nor random allocation of participants. The advantage of quasi-experimental research designs is that they are practical in situations where randomisation is difficult. However, the absence of a control group or randomisation procedures in these types of studies greatly limits the researcher's ability to make cause-and-effect inferences. For this reason, quasi-experimental research is not appropriate for this study because it will not facilitate answering the research questions posed or test the null hypothesis.

#### 4.5.2 Experimental Research Designs

There are a number of main experimental research designs. The most basic of these designs are the pre-test/post-test design and the post-test. Knapp (1998) suggests that although including a pre-test in the study design incurs additional costs and adds complexity to data analysis, its advantage lies in that comparison may be made between the groups prior to the intervention being administered. It allows the identification of differences between the groups at the outset that can be factored into the analysis. A more complex experimental research approach is the factorial design in which two or more variables are manipulated simultaneously. Participants in studies using the factorial design are randomly

assigned to a combination of treatments; however, the participants exposed to one variable may not be the same group that are exposed to the other variables being manipulated in the study. This is known as between-subjects design (Polit et al. 2001).

Another experimental approach to research is the repeated-measures design. This design uses a within-subjects design, which means that the same participants are exposed to more than one treatment. This design has the advantage of allowing equivalence among participants who are exposed to different treatments, but a disadvantage of this design is the carryover effect. This occurs when the first treatment a participant receives influences their response to the second treatment. Polit et al. (2001) propose that the order of presentation of treatments also needs to be randomised when using this design, thereby distributing equally any possible carryover effects.

Perhaps the best known experimental research design in health care is the randomised controlled trial. In medical research this is known as the clinical trial and it is used to test the effect and value of new treatments, procedures or technology (Friedman et al. 1998). This is a prospective design that includes random allocation of participants, large sample sizes, and single or multiple research sites. Clinical trials generally include a pre-test/post-test design, which means they are conducted over a period of time and one key component of this design is that it includes a control group. This experimental research design was regarded as the most appropriate for this study because it would be able to answer research question 1, meet the aims of the study related to this question, and also allow the null hypothesis to be tested, which descriptive or correlational research would not do. The randomised controlled trial design with the use of psychometric tools not only allows any potential psychological effect of 'Open Window' to be identified but also, the size of the effect over time to be measured.



#### 4.5.3 Qualitative Research

In contrast to quantitative research designs, qualitative research designs reject positivism and advocate interpretive and constructivist approaches to research. Many qualitative studies are designed as phenomenological, grounded theory or ethnographic. These approaches to research are based on the belief that there are many different realities and that knowledge cannot be decontextualised or objectified. However, the qualitative component of this study was not based in a particular epistemology. It was based on a descriptive design which Sandelowski (2000b, p337) describes as having the purpose of obtaining ‘straight and largely unadorned (minimally theorised or otherwise transformed or spun) answers to questions of specific relevance’ to the researcher. The purpose of using this design was to obtain a summary of patients’ experiences of ‘Open Window’ and their experience of having a stem cell or bone marrow transplant.

This study was not concerned with using the qualitative approach as its primary research design, as the main purpose of the study was to test the psychological effect of an art intervention. It was clear that the randomised controlled trial was the only possible design that could result in a rigorous study. However, by using a mixed methods research design, the study achieves its other aims of exploring patients’ views on ‘Open Window’ and how it influenced their experience of having a stem cell transplant. Friedman et al. (1998, 2) define a clinical trial as “a prospective study comparing the effect and value of intervention(s) against a control in human beings”. In this study the use of psychometric tools elicited the extent, if any, of potential psychological effects of ‘Open Window’ from which statements about its value for patient care can be made. However, due to the novel nature of ‘Open Window’ as an art intervention, the importance of determining its value for participants cannot be underestimated. By eliciting their views on how they perceive it influenced their experience of having a transplant, a more comprehensive understanding of the true value of art in health is provided and an understanding of the issues that are of concern to patients during this time is also given.

#### 4.5.4 Mixed Methods Research

A mixed methods research approach was used within a randomised control trial design because both quantitative and qualitative methods were required for data collection in order to answer all three research questions and meet the aims of the study. However, it should also be noted that mixed methods of data collection were used in the collection of objective data through the administration of psychometric tools and a survey questionnaire. Mixed methods research involves mixing qualitative and quantitative methods as a means of expanding the scope of and improving the analytic power of studies (Sandelowski 2000a). A number of mixed methods designs have been described in the literature (Tashakkori and Teddlie 2003, Creswell 2003) and include; Sequential explanatory, sequential exploratory, sequential transformative, concurrent triangulation, concurrent nested/embedded, and concurrent transformative.

The design used for this study is the concurrent nested/embedded design and is characterised by a data collection phase in which both qualitative and quantitative data are collected simultaneously. For the sake of clarity, the term 'concurrent embedded' will be used in this study. This mixed methods design has a predominant method that guides the project and a second method that is embedded or nested within it. The predominant method, which is the randomised controlled trial design and the use of psychometric tools and survey questionnaires, addresses a different research question to the second method, which involves the use of semi-structured interviews. The questionnaires address research question 1 and the interviews relate to questions 2 and 3. Although the data sets address different questions, the data are interconnected and each data set is relevant to the other (Figure 4.1). Rogers et al. (2003) conducted a randomised controlled trial and used questionnaires and interviews to evaluate patients' understanding and participation in a trial designed to improve the management of anti-psychotic medication. In this study, the qualitative data were used to coalesce with and extend the understanding of the positive outcomes of efforts to

improve attitudes to medication as measured by the Drug Attitude Inventory. Rogers et al. (2003) concluded that the qualitative component of the trial revealed issues related to the participants' experience, process and outcome of the trial that were relevant to improving the medication practices of patients.

Although mixed method studies are limited in studying quality of life issues in cancer patients and in intervention studies, a number do exist (Keogh et al. 1998, Persson et al. 2001, Larsson et al. 2003, Luoma and Hakamies-Blomqvist 2004). A possible limitation to this research design is that very little is written in relation to how to integrate and present quantitative and qualitative data, although according to Creswell and Plano Clark (2007) both types of data should be presented together using each as a means of broadening the understanding and knowledge in relation to the findings. The qualitative and quantitative data are integrated during analysis and are presented as a whole rather than two separate studies in the findings (Creswell 2003). A review of 118 mixed methods studies by O'Cathain et al. (2008) concluded that researchers using this design do not do this well and need to give more consideration to describing and justifying the design, being transparent about the qualitative component and attempting to integrate data and findings. Morse (1991) and O'Cathain et al. (2007) suggest that qualitative data can be used in a primarily quantitative study to examine issues that can not be quantified and this is particularly important in studies that use questionnaires to study quality of life issues in particular patient groups, for example, patients with cancer. As discussed in chapter 3, using quantitative methods such as questionnaires in cancer research related to quality of life issues and living with a life threatening illness, does not reflect their abstract and complex nature. Mixed methods research using quantitative and qualitative methods for data collection is important in studies concerning quality of life because it allows the researcher to understand its meaning from an individual perspective and provides insight into how this may influence a patient's experience and response to illness (Norman 2003). Perhaps even more importantly, these types of data can provide information that is meaningful to

healthcare staff involved in the development of cancer services at local, national and even international level (McCabe et al. 2007).

#### *4.5.4.1 Placebo Effect*

It is possible to argue that patients' participation in a clinical trial may heavily influence their response and this is particularly relevant in terms of conducting interviews. Although it is not feasible to address this issue or prevent it in the context of this clinical trial, conducting a qualitative study in the same setting when this trial is complete will either support the qualitative data obtained in the trial or differences in findings may suggest that participation in the trial, or as it is also referred to, the placebo effect, influenced what the participants reported (Richardson 2000). The placebo effect is described as the 'symbolic significance of a treatment in changing a patient's illness' (Benson and Friedman 1996, p194). In clinical trials, blinding is used in an attempt to eliminate this, particularly in drug trials. Blinding is not common for psychological or sociological interventions as it is not practical, but perhaps more importantly as Anthony (1993) suggested in relation to complementary therapy, that the therapist is part of the intervention. This is particularly relevant in this study as blinding is not possible due to the presence of 'Open Window' technology in the room of those participants allocated to the intervention groups and their total control of the system using a remote control. It will be obvious to the participant which group they have been allocated to. Therefore, this study will be an unblinded trial in which the researcher and participant are aware of the group allocation (Friedman et al. 1998). Other issues related to un-blinded trials will be discussed in the next chapter.

#### *4.5.4.2 Knowledge Underpinning Mixed Methods Research*

Researchers conducting mixed methods research need to consider the issue of which paradigm perspective it falls into. The philosophical underpinnings of quantitative and qualitative research have been outlined above; however, some

researchers believe that these are so diverse that they can not be integrated when discussing the philosophical underpinnings of a study that uses both methodologies. This is an ongoing debate in the literature (Sandelowski 2000a, Greene and Caracelli 2003, Tashakkori and Teddlie 2003) although according to Creswell et al. (2003) many researchers conduct mixed methods research regardless of the paradigm issues. These authors suggest that researchers do not choose a particular research design because of its underlying philosophy, but rather choose it based on its ability to achieve the purpose of the study in a way that reflects the context in which it takes place.

Greene and Caracelli (2003) propose that using multiple paradigms in designing a study is acceptable but note that the researcher needs to make them explicit, provide rationale for using them and honour them throughout the study. Tashakkori & Teddlie (2003) agree that this is what should direct the decision in choosing a particular research design; however, they express concern that researchers conducting mixed methods research do not explain satisfactorily the philosophical notions that influence the research design. This implies a lack of reflectivity and critical development of the study, and results in mixed method studies failing to achieve their full potential in terms of leading to further inquiry and overall reliability.

#### *4.5.4.3 Pragmatism: the philosophical foundation of mixed methods research*

Pragmatism has become well recognised as the most appropriate philosophical basis for mixed methods research (Patton 1990, Tashakkori and Teddlie 1998, Tashakkori and Teddlie 2003, Creswell 2003). According to Cherryholmes (1992) it evolved from the work of philosophers such as Peirce, James, Mead and Dewey, whose pragmatist philosophy was also a key influencing factor in the development of Benson's (1993) theory of aesthetic absorption as discussed in chapter 1. Although it has many forms, it is generally based on a number of key principles (Creswell 2003, Tashakkori and Teddlie 2003, Burke Johnson and Onwuegbuzie 2004) the first of which is that, unlike qualitative and quantitative

purists who believe that the associated paradigms have no areas of commonality, pragmatism does not commit to a singular philosophy or knowledge. When applied to research, this allows researchers to incorporate both quantitative and qualitative principles when deciding on what methods best suit the purpose and context of their study. The second is that knowledge is both constructed and evolves from the reality of subjective human experience. This principle almost seems to suggest that all research should include mixed methods; however, the previous principle indicates that this is not the case and that, depending on the purpose of the research and the research question/s, a single research methodology may be the most appropriate. The third principle relates to the dynamic nature of truth and how research that acknowledges the well-established dichotomy between the mind and reality produces only tentative findings. Burke Johnson and Onwuegbuzie (2004) suggest that truth is provisional and obtained to some degree only by experimenting and exploring experiences, and even that is not constant. Everything changes, even paradigms, and this is a central component of pragmatism. This does not imply that paradigms and the knowledge underpinning them are not necessary to inform and guide research methodology; it merely suggests that describing and critically appraising them allows researchers to contextualise research and present findings that relate to a particular time, place and conditions.

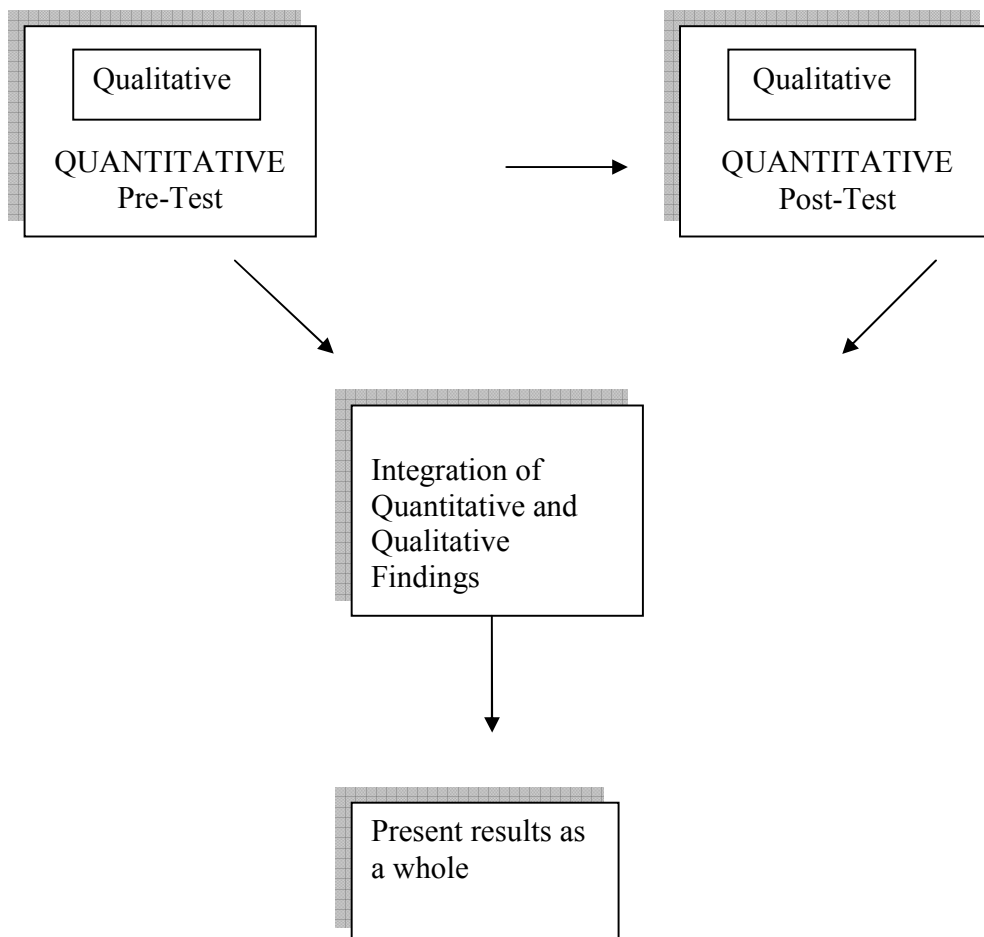
The principles underlying pragmatism are clearly expansive and its apparent lack of allegiance to a single paradigm may encourage mixed method researchers not to document the rationale for their chosen methods and underlying knowledge assumptions (O'Cathain et al. 2008). As already discussed, this weakens a study and suggests that although pragmatism as a philosophical foundation of mixed methods research facilitates the incorporation of different schools of thought in a research design, these need to be explicit and clearly documented.

Mixed methods research with its underlying philosophy of pragmatism is the most appropriate design for this study because it allows the collection and

analysis of qualitative data within the overall quantitative framework of a clinical trial. Pragmatism acknowledges that within a quantitative research design such as this study, qualitative research may provide unknown or unexpected data and if interviews are structured appropriately, these may prove useful in explaining and expanding the quantitative results.

Figure 4.1: Visual representation of the embedded design of this mixed methods study.

### Experimental Methodology



#### **4.6 Study Protocol**

In keeping with the process and guidelines in relation to conducting experimental research, a study protocol outlining the topic, research question, aims of the study, hypothesis and study methodology was developed (Appendix 3).

#### **4.7 Data Safety and Monitoring Committee**

It is recommended that a data safety and monitoring committee (DSMC) be established in all clinical trials where the risk of a treatment is unknown and there is a possibility of adverse outcomes (Wittes 1993, Yusuf et al. 1993, Cairns 2001). The primary concern of the DSMC is the protection of the trial participants by ensuring that there is a balance between the possible risks and potential rewards for its participants (Cairns 2001, Grant et al. 2005). Wittes (1993) suggests that even psychological studies, which are generally regarded as harmless, require external monitoring. This view is supported by Yusuf et al. (1993) but they, along with Wittes (1993) and Grant et al. (2005), conclude that a single independent individual may take on the role of the DSMC in smaller unblinded studies. The steering committee of 'Open Window' study, whose population is relatively small in clinical trial terms (n=400), agreed that an independent individual with expertise in research and psychology would be appropriate. A psychologist with experience in health care research and who is unconnected with the intervention or the research site agreed to take on the role of independent monitor and review all data and interim findings. A report of the interim findings as presented in this thesis will be submitted to the independent monitor for review when analysis is complete, which is expected to be in September 2008.

#### **4.8 Clinical Trials Registry**

This protocol is registered and available for viewing by the general public on the website, [www.clinicaltrials.gov](http://www.clinicaltrials.gov). This web site is a free service run by the United States National Institutes of Health and was developed by the National Library of



Medicine. Its purpose is to increase public awareness and access to information relating to clinical trials worldwide and also, Section 113 of the Food and Drug Administration (FDA) Modernisation Act mandates registration with ClinicalTrials.gov of drug trials. The ‘Open Window’ study is not a drug trial; however, it was registered because ‘The International Committee of Medical Journal Editors’ (ICMJE) requires registration of a clinical trial in order for its findings to be considered for publication.

#### **4.9 Determination of Data collection tools**

Due to the novel nature of this study a number of issues were considered when deciding on what data were relevant and how they should be collected.

Although quality of life is a concept used in relation to all aspects of life, this study is concerned specifically with measuring aspects of health related quality of life (HRQoL). Naughton and Schumaker (1996) describe this as quality of life assessment conducted from a health or medical perspective. As discussed in chapter 3, studies by Zittoun et al. (1999) and Frick et al. (2004) have shown that quality of life assessment does not correlate with physical morbidity alone but is also influenced greatly by emotional subscales such as anxiety and depression. This is particularly true of patients with haematological malignancies where studies have found that anxiety and depression are key risk factors of diminished quality of life and represent the most common emotional response (Molassiotis et al. 1996, Sellick and Crooks 1999, Kelly et al. 2002, Montgomery et al. 2002). It is also apparent that the inclusion of HRQoL measures, such as anxiety and depression is becoming a common occurrence and this is probably mainly due to the United States Food and Drug Administration now recognising the benefits to HRQoL as a basis for approval of new anticancer drugs (Bottomley 2002).

#### 4.9.1 Psychometric Tools

Based on the purpose of this study and the literature review presented in chapter 2, tools to measure the primary outcomes relating to the main emotional responses that adversely affect HRQoL, anxiety, depression and distress, were used to assess changes in levels of these emotional responses over time. Following discussions with the research team, consultant psychiatrist and the senior clinical psychologist with the hospital's psycho-oncology team, the decision was made to use two instruments to measure the outcomes of anxiety, depression and distress. The Hospital Anxiety and Depression Scale (Zigmond and Snaith 1983) (Appendix 4), which measured the primary outcomes relating to levels of anxiety and depression, and the 'Distress Thermometer' (Roth et al. 1998) (Appendix 5), which measured levels of distress were regarded as the most appropriate. They were deemed suitable as they are commonly used in cancer research, are regarded as valid and reliable within this patient group, they correlate well together (Trask et al. 2002, Ransom et al. 2006, Jacobsen et al. 2005) and contain few questions, thus minimising patient burden. The HADS and DT are also recognised as having the ability to detect changes over time (Montgomery et al. 2002, Trask et al. 2002, Katz et al. 2003). These instruments meet Fitzpatrick et al's (1998) eight criteria for selecting patient-based outcome measures in clinical trials, which include appropriateness, reliability, validity, responsiveness, precision, interpretability, acceptability and feasibility. Permission to use the HADS was obtained through Psycho-Oncology Services at St. James's Hospital who had purchased the right to use it in the hospital. Permission to use the DT was obtained directly through the NCCN (Appendix 6).

##### *4.9.1.1 Validity and Reliability Testing*

Quantitative measurement of concepts, attributes or constructs is thought to provide objectivity, precision and clarity (Polit et al. 2001), therefore questionnaires are widely used to gather data. Reliability and validity are the main criteria by which the quality of a quantitative measure is determined (Polit et al. 2001, Pallant 2007). These are two different but interlinked concepts; for

example, if a questionnaire is not found to be reliable then it cannot be considered valid.

Validity refers to the degree to which a questionnaire measures the construct that it was designed to measure (Knapp 1998, Polit et al. 2001, Pallant 2007). There are a number of ways in which validity can be assessed, which include face validity, content validity, and construct validity; however, fundamentally, validity involves assessment against a 'gold standard' (Bowling 2005).

#### *4.9.1.2 Validity and Reliability of the HADS and DT*

The HADS and DT are used in a wide variety of cancer studies when measuring levels of anxiety, depression and distress as key determinants of quality of life (Roth et al. 1998, Montgomery et al. 2002, Akizuki et al. 2003, Hoffman et al. 2004, Akizuki et al. 2005, Jacobsen et al. 2005, Hegel et al. 2007, Gessler et al. 2008). These instruments are also widely used in studies specifically related to bone marrow or stem cell transplantation (Wettergren et al. 1997, Keogh et al. 1998, Zittoun et al. 1999, Hjermstad et al. 1999, Trask et al. 2002, Sherman et al. 2004, Prieto et al. 2005, Lee et al. 2005, Ransom et al. 2006, Grulke et al. 2007).

The HADS is a 14 item self-assessment scale developed by Zigmond and Snaith (1983) for measuring levels of anxiety and depression in hospital settings. Seven items relate to the subscale anxiety (HADS-A) and seven relate to the subscale depression (HADS-D). A cut-off score of 8 or above is recommended by Zigmond and Snaith (1983) as an indication of the presence of significant mood disorder. Factor analysis of the HADS from a large cancer population (n=1474) by Smith et al. (2002) and a review of the literature (747 papers) on the validity of the HADS by Bjelland et al. (2002) supports this and reports that this cut-off score achieves an optimal balance between sensitivity and specificity. These papers also conclude that the subscales of the HADS, that is, HADS-A and HADS-D are more effective at detecting clinical cases of anxiety and depression than residual scores. In this study the Cronbach alpha coefficient for HADS-A

was .803 and HADS-D was .717, reflecting a good level of internal consistency reliability (See Table 4.1 and Table 4.2).

Table 4.1 Reliability of HADS A

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.803	.792	7

Table 4.2 Reliability of HADS D

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.717	.689	7

The DT is a single item self-assessment scale developed by Roth et al. (1998) for assessing psychological distress in patients with cancer. Although a relatively new psychometric tool, it has been used in a number of international cancer studies (Roth et al. 1998, Trask et al. 2002, Akizuki et al. 2003, Hoffman et al. 2004, Jacobsen et al. 2005, Lee et al. 2005, Akizuki et al. 2005, Ransom et al. 2006, Hegel et al. 2007, Gessler et al. 2008). According to Hoffman et al. (2004) the DT has a good internal consistency with a reported alpha coefficient of .81. In this study, the Cronbach alpha coefficient was .731 reflecting a good level of internal consistency reliability (See Table 4.3). Many validation studies (Akizuki et al. 2003, Patrick-Miller et al. 2004, Ransom et al. 2006) have reported that a cut-off score of 4 provides the greatest sensitivity and specificity. These studies and others (Roth et al. 1998, Trask et al. 2002, Akizuki et al. 2005, Jacobsen et al. 2005, Gessler et al. 2008, Zwahlen et al. 2008) report a good correlation between the DT and HADS, thus confirming it as a valid instrument for screening for and measuring distress in cancer patients.

Table 4.3 Reliability of DT

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.652	.731	18

#### 4.9.2 Expectations/Perceptions tool

The third instrument included in this study was a questionnaire containing a single question relating to patients' perceptions and expectations of having a stem cell transplant (Appendix 7). This questionnaire was included because literature from the United States relating to the evaluation of design/art projects in health care institutions suggests a focus on patient perceived quality of care and staff retention as outcomes in evaluating the effect of art and design projects in health care environments (Ulrich 2003, Sadler 2004, Ulrich et al. 2004). Although 'Open Window' is an art intervention and not regarded as a design project, inclusion of such a question was relevant to this study because of its novel nature. The literature discussed in chapter 2 focuses very much on the psychological aspects of having a life threatening illness and its effect on psychological well-being; however, it was important to consider that any psychological response may manifest in terms of perceived satisfaction with care. The questionnaire developed for this study contained a single scale asking participants to rate their experience of having a stem cell transplant on a 5-point scale ranging from much worse than expected to much better than expected (Crow et al. 2002). In order to determine the factors contributing to each participant's rating, they were asked to list 3 things that they found to be positive about their experience of having a stem cell transplant and 3 things that were negative.

Satisfaction was not used in this questionnaire because it is a relative concept and according to Crow et al. (2002) can only be measured against individual expectations or perceptions. In other words, what one person perceives as satisfactory, another may perceive as totally unsatisfactory. In a systematic review of literature relating to measurement of satisfaction with healthcare, Crow et al. (2002) note that being satisfied with a service does not automatically imply that the service is high quality, it merely indicates that the standard of service was adequate and that satisfaction and dissatisfaction are different constructs.

#### 4.9.2.1 Validity and Reliability of Expectations Questionnaire

Single-item questionnaires have been reported as less reliable than multi-item questionnaires (Fayers and Machin 1998, Sloan et al. 1998); however, other studies suggest that this is not the case and have found similar levels of reliability when both types of instruments are compared (Gardiner et al. 1998, DeBoer et al. 2004). Reliability testing of this questionnaire was conducted on a post hoc sample of 10 patients using the non-parametric Spearman rho statistical test. This test demonstrated significant correlation at 0.01 level (See Table 4.4).

Table 4.4 Reliability of Expectations Questionnaire

			Experiences of having a stem cell transplant	Experiences of transplantation 2wks later
Spearman's rho	Experiences of having a stem cell transplant	Correlation Coefficient	1.000	1.000(**)
		Sig. (2-tailed)	.	.
		N	10	10
	Experiences of transplantation 2wks later	Correlation Coefficient	1.000(**)	1.000
		Sig. (2-tailed)	.	.
		N	10	10

\*\* Correlation is significant at the 0.01 level (2-tailed).

#### 4.9.3 'Open Window' Questionnaire

##### 4.9.3.1 Initial Design and Development

This questionnaire was based on survey research and was designed specifically for the purpose of evaluating patients' views and use of 'Open Window' (Appendix 8). The survey design was used because it was concerned with collecting new data from a large number of patients within an explicit, systematic and standardised sampling framework and is ideal for collecting data relating to behaviour, events, attitudes, opinions and reasons (McColl et al. 2001). However, the novel nature of 'Open Window' meant that the content and structure of this questionnaire were not regarded as definitive and it is expected that the qualitative data from this study will provide more defined constructs to be included in future development and testing of this questionnaire.

An initial survey using the ‘Open Window’ questionnaire was conducted to assess the participants’ views and behaviour in relation to how they used the ‘Open Window’ system. It comprised 31 questions in total, which were divided into 5 sections. The first section contained 11 statements that participants were asked to respond to using a six point Likert scale ranging from Strongly Agree to Strongly Disagree. A ‘not applicable’ option was also included as this was a unique art intervention, with nothing written specifically on the topic of how art may help patients with a life threatening illness, undergoing intensive treatments in a confined environment for 3 – 6 weeks at a time. The content of these statements was based primarily on feedback from numerous patients who had been diagnosed with a haematological malignancy and were receiving treatment in the unit. Prior to devising the questionnaire, I interviewed 10 patients about their experiences in the unit and how they felt about their environment. The responses from the patients were documented and summarised (Appendix 9) and were useful in devising questions 1-2, and 8-11. This fieldwork was very useful not just in gaining information about patients’ views but it also gave me an opportunity to become familiar with the physical environment and its restrictions. Accessing patients and talking with them helped me to ensure that the study was realistic and give me a greater understanding of the issues for potential participants, thus making recruitment a less daunting prospect.

The original concept of ‘Open Window’ as a virtual window by its creator, Denis Roche, as a medium through which art works would be used to provide participants with an ambient, relaxing atmosphere and connection with the outside world is reflected in questions 3,5,6, and 11. Questions 1,2,4,7,8,9 and 10 reflected the possible psychological response that participants might have to ‘Open Window’.

Section 2 contained 8 questions and explored the types of images the participants preferred on the ‘Open Window’ system. Participants were asked to indicate their preferred type of art work using a 5 point Likert scale ranging from

‘Strongly Agree’ to ‘Strongly Disagree’ in questions 12 - 18. The option of stating a preference for TV was included in question 19.

Section 3 contained 5 statements (Q20-Q24) that explored how the participants used ‘Open Window’ and their views on the technology. The first statement related to whether or not the participants were able to use the ‘Open Window’ Technology. The second statement related to the preferred time of day for looking at ‘Open Window’. The third statement related to the length of time they viewed ‘Open Window’ on a daily basis and the fourth statement was concerned with the number of days per week they viewed it. The fifth statement asked participants to indicate how many times during each day they turned on ‘Open Window’. Patients were given a number of possible responses to these statements and responded to each statement by ticking the box that corresponded to their experience.

Section 4 contained 6 items (Q25-Q30) and explored which type of image was most popular with patients (Q25-Q28) and included the option of stating a preference for the accompanying music (Q29) and the television (Q30). Participants were asked to indicate the frequency, with which they viewed each type of art work, chose to listen to the accompanying music or watched the television using a 5 point Likert scale.

Section 5 was an open invitation to the participants to document any comments they had about ‘Open Window’ that they felt were relevant to their experience and had not been addressed in the questions.

Even though all participants were required to turn on the ‘Open Window’ system for a minimum of 15 minutes per day, a sixth option of ‘Not Applicable’ was included in the Likert scales. The reason for including this option was that in the event of equipment failure or if the participant was too unwell to turn the system



on, or if the patient chose not to have images from home or of a scenic location of their choice, they would have an option to choose on the scale.

#### *4.9.3.2. Testing the 'Open Window' Questionnaire for reliability*

Reliability of a questionnaire refers to its ability to measure consistently and accurately what it was designed to measure (Knapp 1998, Polit et al. 2001). Key indicators of a questionnaire's reliability are its stability and internal consistency (Polit et al. 2001, Pallant 2007). Stability is defined as 'the extent to which the same scores are obtained when the instrument is used with the same people on separate occasions' (Polit et al. 2001, p305). The process used to assess this is test-retest. A disadvantage of test-retest as an indicator of reliability is that participants' responses may be influenced in the intervening time due to various personal experiences. When testing the questionnaire for stability, it was clear that while the participants' views on 'Open Window' could possibly change over a short period of time due to developments in their physical and psychological condition following treatments, it was expected that their memory of how and when they used it would remain the same, as this is factual, therefore showing relatively high test-retest correlations. However, due to the requirement of having had previous 'Open Window' experience, only eight patients were identified as being suitable to complete the 'Open Window' questionnaire. Each participant received the 'Open Window' questionnaire by post and was asked to return it in the stamped addressed envelope supplied. All eight participants returned the first questionnaire within a week. Ten days later the questionnaire was posted to the same eight participants; however, on this occasion, only five returned it despite a reminder phone call. The low number of questionnaires meant that test re-test results would not be reliable, therefore, frequencies were calculated for each variable in test 1 and test 2. Results showed an 80-100% repetition in the answers for 20 questions out of a total of 23 in each test. However, these results should be viewed tentatively and further retrospective

testing may prove more reliable due to larger numbers and also patients may be more stable physically and psychologically.

The internal consistency of a questionnaire can be used as a test of reliability. This refers to the extent to which items on a scale relate to a central or underlying attribute (Polit et al. 2001, Pallant 2007). It is most commonly established using Cronbach's coefficient alpha, which measures how well a set of items measures a single unidimensional latent construct. However, as the 'Open Window' questionnaire does not have one unique construct running throughout, or in each section, establishing internal consistency was problematic. Another option to test reliability is factor analysis; however due to the small sample size (n=36) this was also rejected, although it may be considered for use with the final sample on study completion. The test considered to be the most appropriate for the 'Open Window' questionnaire was a correlation matrix of all scale questions. A correlation coefficient close to 1 or -1 means that questions are strongly correlated; either positively or negatively. The results of this test show that participants responded similarly to questions measuring the same construct, for example, questions 8, 9 and 13 relate to loneliness and family and the correlations for those questions were .078, -.036, .000 respectively; however, as expected many questions did not correlate well because they related to different constructs (Appendix 8a).

#### 4.9.3.3. *Testing the 'Open Window' Questionnaire for Validity*

In some cases, a 'gold standard' to which a new questionnaire can be compared, does not exist, and this is most definitely the case in relation to 'Open Window' and its effect on patients undergoing stem cell transplantation. This is a novel art intervention that is not, to the knowledge of the researcher or providers, available anywhere else in the world, either as a unique art work or an art work in a health care context for patients undergoing stem cell transplantation.

Face validity is concerned with establishing whether the participants perceive the content of the questionnaire as relevant to themselves. This becomes apparent in how they complete the questionnaire as they may not answer the questions, may provide unclear responses or may not take the questionnaire seriously (Black 1999). In attempting to assess face validity, eight patients who experienced 'Open Window' prior to commencement of the study were asked to complete the questionnaire and comment on any relevant issues relating to the content or structure of the questionnaire. They all completed all sections of the questionnaire but did not provide any comments in relation to structure or clarity. This may have been because they had no prior experience of completing survey questionnaires or because the concept of 'Open Window' was so new to them they had no expectations in relation to appropriate content. However, even though the respondents did not comment, it became clear that one section posed some problems as they tended to tick two boxes instead of one. Although only 2 respondents out of a total of eight responded in this way, the list of possible responses was altered in order to ensure that only one option would be ticked by each participant in future.

Content validity relates to the content of a questionnaire being comprehensive and including in a balanced way all aspects of the concept being measured (Bowling 2005). Researchers usually assess this by distributing the questionnaire to a number of people regarded as experts or who are at least familiar with the concept being measured. As 'Open Window' is a novel concept it is assumed that guiding theory is non-existent or, at best, indirectly related. Therefore, the questionnaire was distributed to a panel of 5 consisting of four university lecturers, two of whom had PhDs and one consultant psychiatrist who headed the psycho-oncology team at the hospital. All were experienced in quantitative research methods and questionnaire construction. All five were familiar with the 'Open Window' project with one being involved in its development and delivery to patients from its inception. Each researcher was asked to review each item on a questionnaire in terms of range, relevance and clarity and award a score of

between one and four and include supporting comments when necessary. The maximum score for each item was 20 and all items that scored below this in each of the categories were restructured using comments documented by the reviewers and personal communication (table 4.6). The result of this process was that a further 10 questions were added to the questionnaire and an open section (section 5) that asked each participant to document their views on ‘Open Window’ was included.

Table 4.6 Content Validity scores for ‘Open Window’ Questionnaire

	<b>Range</b>	<b>Relevance</b>	<b>Clarity</b>
<b>Section 1</b>			
Item 1	19	20	19
Item 2	15	17	13
Item 3	20	20	19
Item 4	19	20	19
Item 5	18	20	18
Item 6	18	20	18
Item 7	14	20	20
Item 8	14	19	17
<b>Section 2</b>			
Item 9	20	20	20
Item 10	20	20	20
Item 11	20	20	20
Item 12	20	20	20
Item 13	20	20	20
<b>Section 3</b>			
Item 14	17	20	16
Item 15	18	20	20
Item 16	19	20	16

<b>Section 4</b>			
Item 17	19	20	17
Item 18	20	20	17
Item 19	20	20	19
Item 20	20	20	19

Construct validity refers to whether the data produced by a questionnaire correlates with other related constructs and is regarded as a particularly robust representation of validity; however, it is also regarded as the most difficult to determine (Black 1999, Polit et al. 2001). Bowling (2005) suggests that construct validity is more relevant to psychology or sociology where the variable of interest is not directly observable. Construct validity has not been determined for the ‘Open Window’ questionnaire because questionnaires measuring a similar concept do not exist.

#### 4.9.4 Interviews

Interviews are described as focused, in-depth conversations that are audio-taped and transcribed verbatim and are the most commonly used method of collecting qualitative data (Streubert and Carpenter 2003; Ritchie and Lewis 2003). Although described as a conversation, the purpose and roles of the researcher and participant in an interview context contrast significantly from social conversation. Interviews are conducted for the purpose of eliciting participants’ subjective views, opinions and experiences of the phenomena being studied. Interviews can be classified as structured, semi-structured or unstructured. Structured interviews require that the researcher asks a number of pre-determined questions, the answers to which are generally specific and limited Streubert and Carpenter (2003). Interviews are described as unstructured when the interviewer asks a question to which there is no specific response. The interviewee gives a personal and totally subjective account of the phenomena being studied Streubert

and Carpenter (2003). Interviews are regarded as semi-structured when the researcher introduces a pre-determined set of topics to be discussed during the course of an interview rather than a set of questions. A document called the 'Interview Guide' (Appendix 10) is used to ensure that all relevant topics are covered (Polit et al. 2001).

Semi-structured interviews were used in this study because it allowed the researcher to elicit personal and subjective accounts of specific issues relevant to undergoing stem cell transplantation that were also related to the aims of 'Open Window'. Participants in the control and intervention groups were asked about four topics relevant to patients undergoing stem cell transplantation. The first topic was about their expectations about having a stem cell transplant and was included in order to provide data to clarify and explain the single item questionnaire in which participants are asked to rate the level at which having a stem cell transplant met their expectations. The second topic related to their views on the physical environment and how it made them feel. This was included to help explain the way a person's environment influences their experience of having a stem cell transplant and may demonstrate how 'Open Window' affected their perceptions of their environment. The third issue explored the participants' personal sense of control over their situation and how they experienced and dealt with stress. This was included because retaining or developing a sense of control of one's life, even small aspects of it, is identified in the literature (Fife et al. 2000, Xuereb and Dunlop 2003) as being important for helping patients with a life threatening illness to adjust more positively as it helps them retain or regain a sense of self and self-esteem. Patients in this study had total control over how they used 'Open Window'; therefore, by eliciting their views on the issue of personal control, differences between the intervention and control groups might become evident. The fourth topic included in the interview related to participants' experience of stress. As one of the aims of 'Open Window' was to provide a relaxing and soothing environment, it was necessary to determine participants' perceptions of stress and how they dealt with it.

Participants in the intervention groups were also asked to discuss issues related to 'Open Window'. The main issues included in this part of the interview were participants' overall experience of 'Open Window,' discussion about the images they liked and disliked and how these images made them feel. Data from this part of the interview were used to support the 'Open Window' questionnaire and explain differences between the groups in terms of how participants rated their experience of having a stem cell transplant.

#### **4.10. Study Population**

The target population in this study was all patients undergoing allogeneic and autologous stem cell transplantation (SCT) at the National Stem Cell Transplant Unit. All patients undergoing allogeneic SCT receive their pre and post transplant treatment in this unit; however, many patients undergoing autologous SCT receive their transplant on a day care basis and return to their local or regional hospital for ongoing treatment. They may only attend the haematology day ward on a monthly basis whereas those undergoing allogeneic transplants attend on a daily basis initially followed by weekly or bi monthly visits or as required by their recovery.

The primary settings or location of this study population is the transplant unit that was described in chapter 1 and also the haematology day ward where patients receive treatment post transplant and following discharge from the unit on a daily, weekly or monthly basis depending on their recovery and medical needs.

#### **4.11. Sampling**

Probability sampling was used in this study. This is when all subjects in the target population have a 'known probability' of being included in the sample (Knapp 1998, p105) and according to Polit et al. (2001), it is the only reliable

method of achieving a representative sample in a target population. Due to the differences in the treatment and outcome for patients having an allogeneic SCT and an autologous SCT (Molassiotis 1999, Lee et al. 2001), a type of probability sampling known as stratified random sampling was used. This means that the population was divided into sub-groups and a probability sample selected on an equal, proportional or disproportional basis from each group (Knapp 1998). In this study the target population was divided into the sub-groups A and B, which represent those undergoing an allogeneic SCT, and sub-groups C and D, which represent those undergoing an autologous SCT and those participants eligible for each group were randomly assigned to the intervention or control group.

Another advantage of probability sampling is that it can help researchers to estimate the level of sampling error in a population. Sampling error is described as ‘the difference between population values and sample values (Polit et al. 2001, p243). In this study probability sampling was feasible with sub-groups A and B as all patients who undergo an allogeneic SCT receive pre and post transplant care at the study centre. However, in groups C and D, not all patients who undergo an autologous SCT would be included in the sample as they do not receive pre and post transplant care at the study centre. In order to control for extraneous variables, only those that received pre and post transplant care at the study centre could be included in the sample.

#### 4.11.1 Sample Size

The calculation of sample size for a study is an essential part of conducting a clinical trial and the justification of the sample size estimate is required in study protocols, reports and by many journals for publication (Staquet et al. 1998, Moher et al. 2001). Friedman et al. (1998) and Machin and Fayers (1998) report that clinical trials which fail to consider sufficiently the sample size requirements are unable to detect clinically significant responses to the intervention. This can result in potentially beneficial interventions being regarded as ineffective. Over recruiting is not only a waste of resources but may also result in patients



receiving an intervention that is ineffective. Under-recruiting means that clinically significant responses between groups are not detectable due to the insufficient number of participants (Friedman et al. 1998, Staquet et al. 1998, Devane et al. 2004). Over-recruiting or under-recruiting for studies is, therefore, regarded as unethical (Machin and Fayers 1998, Devane et al. 2004); however while agreeing with the issues related to under and over recruiting for studies, Friedman et al. (1998) and Devane et al. (2004) suggest that sample size calculations done at the design phase may still be too small to achieve the aims of the study and should be regarded as estimates only. The main reason they give for this is that the parameters used in these calculations are estimates also and often emanate from small studies and based on a population that is somewhat different from the study population. They conclude that it is probably better to over-estimate the sample size and stop the study early than under-estimate it.

It is clear that sample size estimation needs careful consideration in the design phase and this should be realistic and achievable within the context and purpose of a study. Although this should be reflected in the final sample size, in view of Friedman et al's (1998) discussion, with explanation, adjustments can be made to sample size as the trial progresses. Certain components are needed to calculate a sample size that will provide sufficient statistical power to identify differences between groups that are clinically significant (Friedman et al. 1998, Staquet et al. 1998, Devane et al. 2004). These include the level of statistical significance chosen by the researcher as appropriate for this study and is represented by the 'P-value' or 'alpha level', the researchers' perceived chance of detecting a difference and finally the estimated 'effect size'. The 'Open Window' study was interested in identifying differences, better or worse, between the intervention and control groups, therefore, two-sided statistical tests for significance were used.

The purpose of a clinical trial is to determine whether a difference in response to the intervention between the groups is a true response or just down to chance. In

attempting to do this, the researcher aims to either accept or reject the null hypothesis, denoted as  $H_0$  (Friedman et al. 1998). If the null hypothesis is actually true in that there is no difference between the groups, it is possible that slight differences may be observed that are due to chance and are not attributable to the intervention. The probability of obtaining the observed difference between the groups, given that the null hypothesis is accepted, is referred to as the 'p value' (Friedman et al. 1998, Devane et al. 2004). In the case of the null hypothesis being accepted, if the p value is small, it implies that the observed difference between groups occurring as a result of chance is small. This means that the researcher should reject the null hypothesis and in the case of this study, state that 'Open Window' does have an effect (positive or negative) on patients' levels of anxiety, depression and distress.

If the observed differences between the groups exist and are substantial but are due to chance, the researcher could reject the null hypothesis inaccurately. This is known as a false positive or type I error. The probability of a type I error occurring is called the significance level and is denoted as  $\alpha$  (alpha). It represents the critical value for the probability of accepting the null hypothesis and is usually set at 0.01 or 0.05 (Friedman et al. 1998) representing a 1% or 5% possibility, respectively, that observed differences between groups is due to chance rather than a true reflection of the effect of an intervention (Devane et al. 2004). Lowering the value reduces the possibility of a type I error occurring but it also increases the sample size required.

If the null hypothesis is not accepted, then it must be rejected. However, the differences between the groups may be quite small with the result that the researcher fails to reject the null hypothesis even though it should be. This is known as a false negative or type II error and is denoted by  $\beta$ . The probability of accurately rejecting the null hypothesis is referred to as the power of a study (Friedman et al. 1998, Pallant 2007). It quantifies the ability of the statistical tests used in the study to identify true differences between groups and is

determined by the statistical tests conducted, the sample size, effect size and the significance level (alpha) (Friedman et al. 1998, Machin and Fayers 1998, Anthony 1999, Devane et al. 2004). When designing clinical studies, most researchers choose a minimum power of 80% or .80, which indicates at least an 80% chance or higher of observing a statistically significant difference between groups if one actually exists, thereby preventing a type II error.

The 'effect size' is the minimum value or difference between groups that would be regarded as clinically meaningful and significant. This can be determined from a pilot study, published data or by a relevant clinical expert; however, it generally appears to be an arbitrary process and, depending on the intervention and its expected effect, will vary between studies (Devane et al. 2004). An effect size of 30% for the intervention in this study was determined by the Director of the transplant unit, who is also an expert in stem cell transplantation for the treatment of haematological malignancies. As 'Open Window' is a unique intervention and this is the first study to evaluate its effect, the effect size is arbitrary. However, this effect was selected as the smallest effect that would be important to detect, in the sense that any smaller effect would not be of clinical or substantive significance. It is also assumed that this effect size is reasonable, in the sense that an effect of this magnitude could be anticipated in this field of psycho-oncology research.

In order to test the null hypothesis that the four group means are equal, alpha (criterion for significance) has been set at 0.05. The test is 2-tailed which means that an effect in either direction will be interpreted and, with a minimum power of 80%, a sample size of 100 in each of the 4 groups is necessary to yield a statistically significant result. This computation assumes that the mean difference is 1.66500 (corresponding to means of 5.55000 versus 3.88500) and the common within-group standard deviation is 4.14000 (Keogh et al. 1998).

The number of patients eligible and willing to participate in studies relating to psychological adjustment following diagnosis and treatment for haematological malignancies appears to be high. Approximately 60% (n=125) of patients admitted to the study centre per year undergo a stem cell transplant. Sixty undergo allogeneic transplantation and 65 undergo autologous transplantation. In a study by Keogh et al. (1998), 100% of patients agreed to participate in a study exploring the psychosocial adjustment of patients and families following bone marrow transplantation. A study by Hayden et al. (2004) that assessed the long-term quality-of-life after sibling allogeneic stem cell transplantation achieved a 90% response rate. Both of these studies were conducted in the same centre as the 'Open Window' study. So et al. (2003) and Kiss et al. (2002) also achieved response rates of 70.9% and 93% respectively in quality of life studies in this population. Based on these data, it was considered conceivable that over a data collection period of 3.5yrs, the target sample size of 400 patients would be achievable. This thesis reports on the set-up phase of the study, the testing of the research instruments, the findings from the qualitative data and the analysis of the quantitative data from the first 68 participants. The final results, based on the achieved target sample size will be the subject of a subsequent published paper.

#### **4.12 Trial Eligibility**

Although this study took place in the national transplant unit, many patients admitted there are not undergoing a stem cell or bone marrow transplant. Some are newly diagnosed with a haematological malignancy whereas others may be admitted for other related treatments of complications following a stem cell transplant. The population in this study included only patients undergoing stem cell or bone marrow transplantation. Stratified random sampling was used, and inclusion and exclusion criteria were established in order to ensure that only those patients were recruited for the study.

#### 4.12.1 Inclusion Criteria

Patients admitted to the National Transplant Unit for autologous or allogeneic stem cell transplantation who:

- are over the age of 16
- provide consent to participate in the study (parental/guardian consent required if aged 16-18yrs)
- can read and speak English reasonably well
- do not have communication difficulties, intellectual disabilities or known mental illness
- will have received treatment and follow-up care as an in-patient in the National Transplant Unit following transplantation

#### 4.12.2 Exclusion Criteria

- Patients who are not undergoing stem cell transplantation
- Patients who do not provide consent to participate in the study
- Patients who have experienced 'Open Window' on a prior admission
- Patients who receive treatment and follow-up care in a different hospital following transplantation

### **4.13 Ethical Considerations**

#### 4.13.1 Ethics of Clinical Trials

The ethics of ensuring the patient receives the best treatment and randomisation are constantly and have consistently been debated over the years in relation to clinical trials (Friedman et al. 1998). The ethical argument against randomisation is that it deprives approximately half of the study population and all those outside the study population of a potentially better and more effective treatment than the standard one. However, if the researcher does not truly know what the effect of a

treatment will be or whether one is better than the other, then there is no ethical concern with randomisation. This is known as the uncertainty principle or clinical equipoise and is supported by Friedman et al. (1998) and others (Ashcroft 1999, Lilford 2003, Robinson et al. 2005). Debate also exists as to where this uncertainty or equipoise should exist or with whom; for example should the uncertainty of the effect be with the patient, the researcher or the wider health care community? Overall most agree that although perhaps vague and ambiguous, equipoise in relation to a new intervention should exist and needs to be addressed and clarified by the researcher prior to the commencement of a study.

The novel nature of 'Open Window' as an intervention in the treatment of patients undergoing stem cell transplantation, establishes equipoise in this clinical trial. The effect of art in health care has not been evaluated in this way before and as discussed in chapter 1, methodological issues limit the findings from those studies that have attempted to evaluate the effect of art in health care environments (Ulrich 1983, Staricoff et al. 2001). Therefore, uncertainty as to its effect existed in patients, the wider medical community, art community and I as the researcher.

#### 4.13.2 Protecting the participants

Guidelines produced by The Declaration of Helsinki state that research involving human subjects must not take priority over the interests and rights of the individuals (World Medical Organisation 1996). The importance of addressing ethical considerations is an essential component of any study and is the responsibility of the researcher to ensure that participants' rights are protected before, during and after a study (Polit et al. 2001, Burns and Grove 2005). Ethical issues relevant to this study will be discussed with reference to the main ethical principles of Beneficence, Non-maleficence and Autonomy.

#### *4.13.2.1 Beneficence*

This ethical principle refers to a researcher's obligation to do 'good' or ensure that patients or subsequent patients benefit from participation in the study. This requires the researcher to maximise possible benefits and minimise possible harms (National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research 1979). In relation to research it means that the topic has relevance for clinical practice and the study is feasible (Bindless 2000). In order to ensure that patients receive the benefits from the findings of this study as soon as possible or in the event that 'Open Window' adversely affects patients, an independent person will review the data half way through the study. This means that if an adverse effect or significant benefits were detected, the study will be stopped at this stage. This will minimize adverse effects or ensure that all patients, and not just those taking part in the trial, will receive the benefits of 'Open Window' as soon as possible.

#### *4.13.2.2 Non-maleficence*

Non-maleficence refers to the ethical principle 'Above all, do no harm' (Polit et al. 2001), and is particularly relevant for this study. The participants in this study may be regarded as 'vulnerable' as they have a life-threatening illness and are in isolation to prevent infection and to undergo treatment that is often intense and very debilitating. They are anxious and worried about their illness, treatment and its effectiveness. The treatment causes severe physical side effects that could result in the participant being too unwell to complete questionnaires or be interviewed. In order to ensure that patients were only approached for data collection when they are well enough, it was agreed that the researcher would only approach the participants when they said that they felt well enough, and in conjunction with their consultant and unit nursing staff. If they became unwell during the interview or while completing the questionnaires, the process would be stopped immediately. In addition, it was agreed that the researcher would ensure that the participants were aware that they could withdraw at any time if they wished.

Some images of art/nature may be particularly meaningful to individual participants and therefore, may cause some psychological discomfort and distress, but this is hard to predict. It was planned that, if this occurred in this study, participants would have the option available on the remote control system to choose not to view that particular image/s in the future. A review committee was established with the purpose of reviewing all the content before the participants saw it. If content is considered unsuitable it is not passed. All content that has been reviewed and passed by this committee is then signed off by the medical director. This is an attempt to eliminate any overtly disturbing images; however, it is acknowledged that a person's response to any image will be subjective and therefore, cannot be predicted. It was important, therefore, to ensure that supportive measures were in place in order to minimise distress/discomfort caused by the 'Open Window' intervention.

It was planned that, if any participant experienced psychological distress/discomfort as a result of viewing a particular image, or as a result of the interviews, the researcher would talk to the participant about the experience and reassure them. The participant would also be offered the services of the psycho-oncology team who are represented on the research team and were available to support participants if necessary.

#### *4.13.2.3 Autonomy*

The ethical principal of autonomy, is concerned with an individual's right to self determination and respect for a person's right to make informed decisions (Polit and Beck 2004). In research this refers to ensuring that participants provide informed consent, and was an issue in this study. The potential participants had a life threatening illness and were about to undergo treatment that required them to spend long periods of time in restricted isolation. It was important that they did not feel coerced into participating in the study. I, the researcher, who collected the data and had the most contact with the participants, was not connected to the



Unit in any way other than for the purpose of conducting the study. The participants were made aware of this and they were also reassured verbally at each stage in the data collection process, and in writing, that they could withdraw from the study at any time without giving an explanation.

Participants were also informed both verbally and in writing of the nature of the study and the randomisation process so that it was clear to them what role they had and also how the information they provided would be used. In order to ensure that participants understood the information and its implications, they were invited to ask questions at any time about the study and their role in it.

#### *4.13.2.4 Justice*

This ethical principle refers to the participant's right to fair treatment and privacy (Polit et al. 2001). The manner in which participants received fair treatment in this study is evident in how the principles of beneficence, non-maleficence, and informed consent are addressed. The same procedures applied to all participants in this study. Participants were also informed verbally that they could have access to data that they provided at any time and that they would receive a copy of the final report on request (Data Protection Commissioner 2007).

#### *4.13.2.5 Anonymity and confidentiality*

Anonymity was maintained by referring to each participant by number on any documentation published related to the study. All data are stored in a secure office in accordance with the Data Protection (Amendment) Act 2003. Hard copies of participant details and data collected are kept in a secure file to which only I have access. Inputted data for analysis is stored on a password protected personal computer (password known only to me) in a locked office. All records of data will be destroyed five years after completion of the study (Trinity College Dublin 2007). Patient/client records were not removed from the research site at any time during the study.

#### **4.14 Summary**

‘Open Window’ is a novel art intervention currently being used in the National Bone Marrow Transplant Unit. The psychological effect of ‘Open Window’ is being measured and evaluated using a randomised controlled trial design. Mixed methods for data collection and analysis were used to gather subjective data concurrently with objective data. The reason for this is to gain information about participants’ experiences of ‘Open Window’ and to determine any influence it may have on their experience of undergoing stem cell or bone marrow transplantation. All patients admitted to the Denis Burkitt Unit for a stem cell or bone marrow transplant were eligible to join this study. Due to significant differences in physical and psychological responses to treatment, patients undergoing autologous stem cell or bone marrow transplant were randomised separately to those undergoing allogeneic transplantation. This resulted in 4 groups, which power analysis revealed needed 100 participants in each in order to achieve sufficient power. A study protocol was produced and the trial was registered at ClinicalTrials.gov.

Using psychometric tools, the outcomes being measured and evaluated in this study were anxiety, depression and distress. Participants’ views on ‘Open Window’ were also determined using a survey questionnaire. It was also decided to include a single item questionnaire asking participants to give a rating for their overall experience of having a transplant. This was included due to the novel nature of the intervention and lack of previous research to determine where the effect of ‘Open Window’ lay.

The ethical principles of Beneficence, Non-Maleficence, Informed Consent and Justice provide a framework for ensuring that participants were respected and protected throughout their participation in this study.

#### **4.15 Conclusion**

This study used a randomised controlled trial design and mixed methods for data collection and analysis because it allowed all research questions to be answered and aims and objectives to be achieved. The psychometric and survey questionnaires being used to collect data were tested and found to be valid and reliable. An interview guide was used to ensure that topics related to patients' personal experience were discussed but also provided subjective data that was used to inform and explain quantitative data outcomes.

## **Chapter 5: Study Methods**

### **5.1 Introduction**

This chapter outlines and discusses the methods used in this study. Details relating to the site access and recruitment are provided. This is followed by a discussion and outline of the methods chosen for data collection and the decisions that influenced their selection. Data were collected on seven different occasions from participants in this study; the reasons for this are provided in section 5.9. The process for managing the data using SPSS Version 15 and NVivo 7 will be outlined and the statistical tests used for quantitative data analysis will be identified along with a rationale. A pilot study was conducted and issues and developments arising from it relating to the main study are outlined. Ethical approval and issues relating to this study are outlined and discussed. This is followed in the last sections by a description and discussion of the quality initiatives and the use of independent monitoring of data in this study. It is important to note that this is an interim analysis, therefore, findings should be viewed tentatively as they may not reflect the final results. Also, it is not appropriate to comment on accepting or rejecting the null hypothesis at this stage as the *a priori* sample size has not been achieved. One advantage of conducting interim analysis is that the results can be reviewed by the independent monitoring person in order to determine whether or not the study should continue. A significant result at this interim stage would indicate either sufficient benefit of one intervention in one instance or evidence of harm in another, usually resulting in the need to stop the trial.

### **5.2 Ethical Approval**

This study was reviewed by the ethics advisory committee of the School of Nursing and Midwifery, Trinity College Dublin, and received ethical approval from the hospital's Research Ethics Committee (Appendix 11).

### **5.3 Negotiation of Access**

Access to the research site and permission to conduct the 'Open Window' study was sought from the Hospital's chief executive officer, the director of nursing, the relevant hospital consultants and the nurse managers of the stem cell transplant unit. The director of this study is also the director of the transplant unit, therefore permission to conduct the study on the unit was implicit and included permission and support from the other relevant consultants. Gaining permission from the nurse managers in the unit was also straightforward as they were involved in the introduction of 'Open Window' to the unit. Permission from the hospital's chief executive officer and the director of nursing was obtained through the Patient Advocacy Committee (Appendix 12). The patient advocacy committee is a quality initiative within the hospital with external and internal organisational members. The purpose and membership of this committee will be discussed in more detail under the section 'Quality Initiatives' at the end of this chapter.

### **5.4 Recruitment**

There were a number of issues to consider when developing a recruitment process that was effective and efficient for all concerned. The first issue was that all patients undergoing stem cell transplantation (autologous and allogeneic) would need to complete a Trial Registry Form (Appendix 13) whether they agreed to participate or not. If the patient was eligible and agreed to participate in the study, they would then need to provide verbal and written consent. The people regarded as best placed to do this were the two transplant co-ordinators attached to the unit. They see all patients on a number of occasions prior to their admission and know the patients well. They agreed that they would complete the Trial Registry Forms, administer the patient information leaflet (Appendix 15) and if necessary answer any queries, and take consent if the patient wished. They would then inform me of the names of patients who had provided consent (verbal

or written) and forward the trial registry forms to me and I proceeded with the randomisation process (see flow chart, appendix 14). Once successfully recruited, stickers were placed on the front of the participants' charts stating the name of the study and their study number.

If a patient was regarded by the transplant co-ordinator as being too anxious to recruit to the study at the time of their visit to the transplant co-ordinator, they informed me and I contacted the patient by telephone a few days later. If they expressed an interest in participating in the study, I forwarded the information leaflet and consent form by post. On receipt of verbal or written consent I contacted the telephone randomisation service who issued a study number and gave the allocation of the patient.

An important part of the recruitment process being successful was training the transplant co-ordinators. This took the form of a number of meetings with me in which we discussed the overall study protocol, the patient information sheet and consent form. They were both very familiar already with the 'Open Window' project in the unit before the study started and were familiar with the study documentation, particularly the patient information sheet and consent form, as I had sought their contribution and feedback in the development of these documents. Both co-ordinators also had experience in recruiting patients for studies in the past and they assured me that this would not be a difficult process for them. Furthermore, the number of patients eligible and willing to participate in studies with a similar population and context is between 70% and 100% which is quite high (Keogh et al. 1998, Kiss et al. 2002, So et al. 2003, Hayden et al. 2004) thus contributing to their ultimate goal of recruiting 400 patients to the study. This is in contrast to a review of 35 papers exploring why patients do not take part in cancer clinical trials by Cox and McGarry (2003), which identified low accrual rates of between 2-5% in the both the United States and the United Kingdom. The reason for the higher accrual rates in studies with stem cell or bone marrow transplant patients may be that they are usually feeling very well

when admitted to hospital and therefore, do not perceive participation as a burden.

However, I was eager to discuss the issue of bias in recruiting participants for this study in particular in relation to the co-ordinators' personal views and experiences of both art and the use of technology. For example, they may have felt that women would be more responsive to art, therefore, they may expend more time and effort in recruiting them. I felt that through informal guided discussion, I could facilitate a reflective process in which the co-ordinators would become aware of their own views on this and in recognising also, the possibility of an unconscious bias being reflected in their recruitment styles, they would be more aware of how they recruited, thereby limiting or eliminating bias. Informal discussions continued throughout the recruitment process in order to ensure that the recruitment guidelines were followed and to maintain awareness of the possibility of bias in how patients are recruited.

On a number of occasions, the transplant co-ordinators had very limited or no one-to-one contact with patients before they were admitted for transplantation. On these occasions I phoned the patients directly and discussed the study with them. This was successful, with all patients agreeing to take part in the study verbally, thus allowing the randomisation process to take place before the patient arrived on the unit. I anticipated that some participants may have changed their minds about participating in the study on the day of admission, but, this was not the case. All patients showed enthusiasm and appeared interested and happy to contribute. Recruitment for this study was not problematic and the main reason for this was that when patients are admitted for bone marrow transplantation, they are probably feeling better physically and even psychologically than in the previous few months, and were, therefore, more likely to consent to participating in the study. For this reason it was important that consent be an ongoing process as dramatic changes in physical and psychological well-being could be expected undergoing treatment of this kind.

## **5.5 Informed consent**

When eligible patients were being recruited to this study, either I or the transplant co-ordinators gave them a patient information leaflet (Appendix 15), discussed the study with them and answered any questions. Each patient had approximately 5 days to consider the information and decide if they wished to participate in the study. They were also given the opportunity to discuss the information with me if they wished and my contact details were provided on the leaflet. If they agreed to participate they were asked to provide written consent on admission to hospital or before admission if feasible. They signed two copies of the consent form (Appendix 16), which were co-signed by me or the relevant transplant co-ordinator. Participants were made aware at this point that this was not binding and they could withdraw their consent to participate at any time without explanation.

Patients over the age of 16 were eligible to participate in this study. Verbal and written consent was required from the patient and parents if they were between the age of 16 and 18yrs. In the event of this happening, it was planned that I would meet the patient and parent(s) and discuss the study in detail; however, this has not been necessary up to this point in the study as all prospective participants have been above 18 years of age.

## **5.6 Randomisation**

Randomisation is a process that ensures that each participant in a study has equal chance of being assigned to either the intervention or control group (Friedman et al. 1998, Beller et al. 2002, Schultz and Grimes 2002). Randomisation comprises two key processes, the first is the generation of a randomised allocation schedule that is unpredictable and the second is concealment of the sequence until the point of allocation (Schultz and Grimes 2002). The process should prohibit either the potential participant or the people recruiting participants knowing what



the patients' allocation is before they agree to participate in the study. Schulz and Grimes (2002) and Beller et al. (2002) suggest that the person who generated the random allocation sequence should not be involved in recruitment, administering the intervention or evaluating the outcome. The allocation sequence for this study was generated using a computer random number generator package (StatsDirect).

Random allocation of the participants in this study was conducted by a telephone randomisation service. When patients were recruited to the study by the transplant co-ordinators they informed me and I then contacted the telephone randomisation service. In order to conceal the random sequence to the point of allocation, it would have been more appropriate for the transplant co-ordinators to contact the telephone randomisation service directly when the patient provided consent. However, due to operational difficulties this was not feasible. The person located at this service and who allocated the participant and assigned the study number was independent physically and professionally to the study site and researcher respectively. This reduced the chance of selection bias in allocating patients (Friedman et al. 1998, Roberts and Torgerson 1999, Devane et al. 2004). The person at the telephone randomisation service allocated the participant's study number and group from a predetermined list. The telephone randomisation service also maintained a record of the date, time, person requesting the randomisation, and hospital identity number (Appendix 17) of each participant.

Simple, blocked and stratified are three approaches to fixed allocation. Simple randomisation is unrestricted and described by Schulz and Grimes (2002) as the ultimate method of ensuring unpredictability and preventing bias. However, they also suggest that its ability to provide truly unpredictable sequences can be disadvantageous because it can cause highly disparate sample sizes in groups. Although this imbalance dissipates with larger sample sizes ( $\geq 200$ ) and towards the end of recruitment, it can be problematic if the researcher needs to conduct interim analyses. In view of this, Schulz and Grimes (2002) and Friedman et al.

(1998) propose that randomisation should be balanced or restricted and this is achieved through blocking. This process guarantees that large imbalances in group sizes will not occur by ensuring that after blocks of every 4, 6 or 8 participants are randomised, the groups are equal in size. Blocking has the ability to limit the predictability of the allocation sequence greatly, but it is still possible, particularly in larger unblinded studies for staff involved in recruiting participants to recognise patterns of allocation. The use of larger block sizes or randomising block sizes can prevent this by making it more difficult to determine where a block starts or stops (Friedman et al. 1998, Schultz and Grimes 2002).

Participants in this study were allocated a study number and randomly assigned to the intervention or control group on a 1:1 ratio. A computer random number generator (StatsDirect) used random block sizes to produce the allocation sequence for this study. Due to the expected differences in responses between sub groups A and B and sub groups C and D, randomisation was stratified. It is arguable that allocation should be unequal, that is, more participants should be allocated to the intervention than control group, for example on a 2:1 ratio. The advantage of this is that more information may be obtained in relation to the intervention, but according to Friedman et al. (1998) this could result in participants being exposed to an ineffective or even harmful intervention needlessly. Equal allocation of participants to intervention and control groups was chosen for this study because it is the more powerful design (Friedman et al. 1998) and is also reflective of equipoise or the researcher's belief that the anticipated effect of 'Open Window' is unknown.

Random allocation of participants in this study required teamwork and co-operation between the research team and the nursing/medical staff on the transplant unit. The reason for this is that patients are cared for in single rooms under very restricted conditions in order to prevent infection. Ensuring that participants who were randomised to the intervention group were admitted to a room with 'Open Window' sometimes required moving a patient to another room

in order to vacate the appropriate one. While this in itself is a straightforward process, each room that is vacated needs to go through a rigorous cleaning process before another patient can occupy it. Therefore, it requires planning on behalf of the nurse manager and can be disturbing for patients who are asked to move to another room. In order to minimise disruption for patients and the nursing staff, the randomisation process was conducted a minimum of 3 days before the patient was admitted. This meant that the nurse manager and relevant staff could be prepared in advance to move patients when necessary.

## **5.7 Pilot Study 1**

Unforeseen problems may arise when conducting a research project, resulting in the need for changes to be made to the study protocol. In experimental studies, if changes are made after the main study has started, all data collected prior to this cannot be included in the study. Polit et al. (2001) recommend that the researcher conduct a small-scale trial run of the main study, the purpose of which is to identify problems related to the study methods and feasibility (Polit et al. 2001). Therefore, a pilot study for this research project was conducted during July-October 2005. Six patients undergoing allogeneic stem cell and bone marrow transplantation were recruited with three randomly allocated to both the control and intervention groups. This was a small sample size due to time limitations. Over the three month period of the pilot study it was vacation time, therefore, the number of patients admitted for stem cell or bone marrow transplantation was somewhat reduced.

### **5.7.1 Establishing relationships**

Prior to conducting the pilot study I held informal information sessions on the ward as I felt that it was important that the staff understood the nature of the 'Open Window' study. Although the nursing managers supported this initiative, attendance at the sessions was poor. Subsequent conversations with nursing management and staff nurses revealed that attending these sessions added to the

staff nurses' perceptions that the study may increase their workload. On reflection I understood the point and felt that as they were not required to contribute to the study directly, they could be informed about the study in another way. It was important that, although they were not directly involved in the study, they understood the concept and the study process so that they could interact appropriately with the participants when necessary. Therefore, I made posters outlining the concept of 'Open Window' and the study details, and placed them in the staff rest room and at both the nurse stations in the unit. The experience of conducting a clinical trial, albeit on a small-scale, was invaluable in allowing me to develop a relationship with the ward staff. In conjunction with the posters, my presence on the ward every day resulted in acceptance and co-operation from the nursing/medical management, staff and cleaning personnel. This was a very positive and important development as the randomisation process in this study created work for the staff in that patients needed to be moved from one room to another on occasion in order to facilitate study participants. When vacated, each room needed to be cleaned meticulously before a new patient could be admitted. It was essential that I used a flexible, understanding and constructive approach to problems that arose in relation to participants being admitted to the appropriate room. I feel that this approach demonstrated understanding of the difficulties the nurse managers faced when ensuring that participants were admitted to the appropriate room and was a key element in maintaining open and positive relations with the ward staff, especially domestic staff.

#### 5.7.2 Recruitment, randomisation, data collection and data management

The pilot study gave me the opportunity to test the recruitment and randomisation system, data collection procedures and to identify data management issues. The recruitment and randomisation procedures ran very well with good communication between me and the transplant co-ordinators in relation to recruitment. However, the issue of informed consent arose as an ethical concern from the pilot study. Although the transplant co-ordinators

recruited the majority of patients for the study, they felt occasionally that some patients would not be able to deal with excessive information during their visits to the day ward due to stress regarding their impending transplant. On these occasions I phoned the patients at home and discussed the study with them. They were asked to think about whether or not they would like to participate in the study. If I received a positive verbal response I proceeded to contact the randomisation service. This meant that some patients had given written consent and others had just given verbal consent prior to randomisation. However, as consent was ongoing all patients were asked to confirm their consent on admission and those who had previously given verbal consent were asked to sign a consent form at that stage.

The randomisation process was effective and allowed for 2-3 days' notice of participant allocation for the nurse managers, so that they could ensure that the appropriate room was vacant.

During recruitment and the provision of a verbal explanation of the study, some participants commented that they knew nothing about art, and, therefore felt that they would not be able to contribute in a meaningful way. In order to prevent alienating or intimidating potential participants, it was decided not to use the term 'art' in describing the 'Open Window' study. Art works were instead referred to as still or moving images.

The data collection point of T5 (day 60 post transplant) raised issues in relation to participant anxiety. Due to ongoing concerns about recovery, treatment success and the degree of graft versus host disease they might experience, levels of anxiety, depression and distress remained high even though they were attending the day ward and were not necessarily in-patients. I suspected that the high levels of anxiety and distress at this point adversely influenced participants' ability to reflect on the experience, which in turn affected their response in relation to the scores on expectations. The persistently high levels of anxiety and

distress suggested that participants did not delineate between their time in restricted isolation and attending the day ward in terms of their recovery. It was the number of days post transplant that appeared to be most relevant to them and influential in terms of experiencing anxiety, depression or distress. This implies that the experience of having a stem cell transplant extends from the day of admission to day 100 and, on this day, patients assess the success of their recovery and chances of survival. It may also have affected their judgement in relation to subjective accounts of their experience of 'Open Window' and stem cell transplantation in the interview. It was decided therefore, following this pilot study, to include an additional data collection point, T7 (6 months post transplant) as patients would have had time to reflect on their experience of having a stem cell transplant and using 'Open Window'. Although it is arguable that other factors such as family circumstances, response to treatment and social support may influence participant responses at this point, it was felt that the chance of this was equalised by the randomisation process. It is also possible to argue that asking patients to score their expectations 6 months after the transplant is too long a time period and their memory of the experience may be diminished. However, it was felt that within the context of recovering from stem cell transplantation and possibly surviving a life threatening disease, time to regain some sense of normality was important before asking patients to evaluate the experience.

## **5.8 Pilot Study 2**

After pilot study 1 was complete and all changes and adjustments had been made, the main study commenced in August 2006. However, it became apparent over the first few weeks of the study that participants in the intervention group could not be offered the complete 'Open Window' service. Due to unforeseen problems with the mobile phone company and internet supplier, there was a ten week delay in providing a fully functional mobile phone (with camera) for families to take home and send back images for the participants. Although all other aspects of the 'Open Window' service were available, the mobile phone

was not, until mid October 2006. However, the study did not stop during this time because the systems in place for recruitment, data collection and provision of the intervention were operating very well and stopping the study may have caused difficulties in starting again. The result of this, however, was that the first nine participants from the autologous and allogeneic groups did not have the option to use the complete 'Open Window' service, therefore, could not be included in the sample numbers for the main study. I regarded this phase of the study as frustrating but also invaluable as a second pilot because it was clear that the systems in place for the study were working well, not only for me as the researcher, but also for the other health care staff involved, particularly the transplant co-ordinators, unit managers and the domestic staff. This phase of the study also provided me with the opportunity to develop my interviewing skills further and get an idea of the general issues that were important to participants.

## **5.9 Data collection**

As this was a prospective longitudinal study, a number of data collection points were included. This type of approach to data collection in this patient population is quite common, with many studies collecting data on 2 - 6 occasions over three or six month periods or even up to one year (Molassiotis 1996, Wettergren et al. 1997, Keogh et al. 1998, Zittoun et al. 1999, Hjermstad et al. 1999, Fife et al. 2000, Lee et al. 2001, Ho et al. 2002, Akaho et al. 2003, Prieto et al. 2005). The number of data collection points and timing depend on the known trajectory of patient treatment and recovery in the short term and long term. Collecting data prospectively over extended periods of time allows researchers to demonstrate changes over time and, in particular, whether or not the independent variable ('Open Window') affects the dependent variable/s (levels of anxiety, depression and distress and patient experience/perceptions). Polit et al. (2001) describe this outcome as essential for establishing causality.

In this study, data were collected from patients in all four groups on seven different occasions ranging from the day of admission to six months later.

(Figure 5.1). These included the day of admission, the day before transplant, seven days post transplant, 18 days post transplant for participants undergoing allogeneic stem cell transplantation and day 14 or prior to discharge (whichever came first) for those undergoing autologous stem cell transplantation, and on days 60, 100 and 190 following transplantation. All questionnaires were administered by the researcher in this study. The first reason for this was to minimise patient burden. The second reason was to ensure that data were collected at the predetermined points and the third reason was to ensure that instruments were complete and filled out correctly. Data collected from 68 participants have been included in this report.

The first fifteen participants from each of the four groups were interviewed on three occasions, pre and post intervention. The first interview took place on admission, the second, prior to discharge and the third was at 6 months post transplant. The purpose of this was to examine individual changes that occurred as a result of an intervention over a significant period of time (Ritchie and Lewis 2003). The qualitative data derived from these interviews were used to clarify, explain and describe the type and nature of change that took place in relation to the specific issues outlined in the interview guide. Issues related to patients' overall experience of having a stem cell transplant also emerged from these data, which had not previously been documented in such detail in the literature. It was felt that these points would capture the main issues and identify key changes or developments in their recovery from a subjective perspective. Fifteen participants from each group was considered to be sufficient as it was apparent from about the tenth interview across the groups that no new information was emerging, thereby making the interviewing process redundant. This point is known as data saturation and in qualitative research is often used to determine sample sizes (Leninger 1994, Polit et al. 2001). A total of 180 interviews were conducted, each one lasting an average of 15 – 20 minutes. Qualitative data were transcribed, stored and managed using the computer package, NVivo 7.



Figure 5.1 Data Collection Points for this Study

Data Collection	HADS	DT	'Open Window' Questionnaire	Expectations Questionnaire	Interview
T1 (Admission)	√	√			√
T2 (Day-1)	√	√			
T3 (Day+7)	√	√			
T4 (Day+18 Allo's) (Day+14Auto's or day of discharge)	√	√	√		√
T5 (Day+60)	√	√			
T6 (Day+100)	√	√		√	
T7 (6/12 PT)	√	√			√

### 5.9.1 Protection of participants

Bearing in mind the possibility that during the course of an interview, the participant might become upset or emotional, I tried to conduct the interviews in a sensitive and caring manner. If a participant became upset, I offered to stop the interview and remained with the participant and comforted them. If the participant wished, they were facilitated to talk to the senior clinical psychologist of the psycho-oncology team who had agreed to provide support to the participants if necessary for the duration of the study. Although about one quarter of the participants became upset (cried), none wished to speak to a psychologist or even terminate the interview. Some even said that they felt

crying was good for them and did not regard it as a negative expression of emotion. As the researcher I always talked directly about what they felt was upsetting them and tried to be empathetic by staying with the participant until they seemed to feel better. Other participants did not cry but it was clear from the tone of their voice, their facial expression and their words that they felt anxious, distressed or even angry. On these occasions I tried to communicate that I understood and empathised by staying with them and addressing difficult issues that participants talked about, such as fear of dying, directly. Even though, especially in the initial interviews, I found it difficult, I tried not to be dismissive or patronising during emotional interviews and focused hard on using active listening. Over time I found this easier and felt that participants were comfortable expressing their emotions during the interviews. It should be noted that relatively few patients became emotional, most appeared to be accepting or pragmatic about their situation.

Participants began to get particularly ill from about seven days after the transplant; this meant that I needed to be mindful when approaching them to collect data as I did not want to add to their burden. They found it difficult to get up and have their shower or bath in the mornings. The ward routine was also particularly busy with doctors' rounds, and visits from the nutritionist and other health care staff. Lunch was given out at midday, and it was after this at approximately 12.30 that I generally aimed to collect data. Late afternoon at around 4pm was also a good time to collect data as they would have had an afternoon rest.

## **5.10 Data Analysis**

### **5.10.1 Quantitative data**

Inferential statistics were used in this study to indicate how the null hypothesis would be tested following full data collection and how conclusions would be drawn about the effectiveness of 'Open Window' on the psychological well being of this patient population. These types of statistics allow researchers to

determine the likelihood of conclusions drawn being true (Norman and Streiner 2000). Data from the questionnaires were managed and analysed using a computer package called 'The Statistical Package of the Social Sciences' (SPSS), version 15.0 for windows (2005).

#### *5.10.1.1 Missed Data*

Missing data can be problematic in clinical trials in that power to detect change over time may be reduced or if the missing data was due to a non-random event, bias may be introduced (Fairclough 1998). In this study missing data (missing values) were minimal as the questionnaires were administered by the researcher. However, due to the life threatening nature of the illness and treatment, missing data were expected. Two participants undergoing allogeneic transplantation were too unwell to have the transplant, therefore only two data collection points were completed. As consent was ongoing, three patients declined to continue providing data at various data collections points. One had recurrence of her disease and was extremely unwell, the other two patients were recovering at home and I felt that phoning them in the morning was inconvenient and they sounded anxious. This may not have been the reason for them leaving the study but nonetheless I felt it may have been a contributing factor and thereafter, phoned participants after lunch. I also started every interview by asking them if it suited them to talk at that particular time. No patients died in the group undergoing autologous transplantation but there was a 14% (10 participants) attrition rate due to death in the group undergoing allogeneic transplant. Given that recruitment for this study is just under half way through, and that data are only collected for the first six months post transplant, this is similar to the outcome of studies by Hayden et al. (2004) and Keogh et al. (1998) that suggest a mortality rate of approximately 30% at 1-5 years post transplant.

Participants who died were deleted cases, and for all other cases, data were analysed when available. Repeated measures analyses the differences between the groups over time, therefore if data are not available for a participant for one

or more time points, then it is automatically excluded from repeated measures analysis. Keeping records of those who died would have skewed overall results and also group comparisons as deceased participants were unequally distributed among the autologous and allogeneic groups.

#### 5.10.1.2 *HADS and DT*

In order to detect and analyse changes over time, repeated measures analysis of variance (ANOVA) was applied to anxiety, depression and distress levels. This test provides detail regarding the main effect for time, the main effect for groups and an interaction effect (Polit et al. 2001). When a dependent variable, that is, levels of anxiety, depression and distress is measured repeatedly for all sample members across a set of conditions, it is called within-subjects factor. When the same dependent variables are measured on independent groups of sample members where each group is exposed to a different condition, it is known as between-subjects factor. When both within-subjects factors and between-subjects factors exist in an analysis it is known as repeated measures ANOVA with between-subjects factors (Field 2005). The variance between the groups is represented by an F ratio with a large F ratio indicating greater variability between the groups (due to the independent variable) than within groups (due to error). The F ratio refers to degrees of freedom and is denoted by df or d.f. (Norman and Streiner 2000, Pallant 2007). This test provides detail regarding the main effect for time, the main effect for groups and an interaction effect (Polit et al. 2001).

SPSS tests to see if it is acceptable to conduct an ANOVA on data by assessing if the data satisfies relevant assumptions. In between-group ANOVA the accuracy of the F-test is based on the assumption that scores in different conditions are independent. However, in repeated measures this assumption is violated because the scores are more likely to be related because the same participants provide them (Field 2005). This means that the F-ratio will not be as accurate. If data violates Mauchly's test of Sphericity, that is,  $p < .05$ , it means that there are

significant differences between the variances of differences. Ultimately this results in a loss of power (Field 2005). In this instance other corrections are applied to produce a valid F-ratio. These corrections are based on estimates of sphericity recommended by Greenhouse & Geisser (1959) and Huynh & Feldt (1976). Both of these estimates provide a correction factor that is applied to the degrees of freedom used to assess the observed F-ratio. The Greenhouse & Geisser correction is used when the estimates of sphericity are less than .75 and the Huynh & Feldt correction is used when estimates are above .75 (Field 2005).

#### 5.10.1.3 *'Open Window' and Expectations Questionnaire*

Due to the categorical nature of the data from these questionnaires, frequencies and crosstabulations were used in the analysis.

#### 5.10.2 Qualitative data

According to Tashakkori and Teddlie (2003) when planning data analysis procedures for mixed methods studies, the researcher needs to consider whether the purpose of the study is exploratory or confirmatory. Exploratory research is used to generate or expand on theory and is descriptive in nature, whereas confirmatory research is primarily concerned with theory or hypothesis testing. Quantitative studies can be both, but qualitative research is generally regarded as exploratory (Lincoln and Guba 1985). The main aim of this study was to test the null hypothesis and measure outcomes in relation to distress, anxiety and depression, therefore the purpose of this study was confirmatory. However, other aims of this study were to determine whether 'Open Window' influences participants' experience of having a stem cell transplant or has a long-term effect on a person's experience of having a life threatening illness. It is clear that this study also has a clear exploratory purpose, but the semi-structured design and content of the interviews suggest a confirmatory purpose also. For example, in the interviews, each participant is asked about their expectations in relation to having a stem cell transplant. These data are important not just in generating

information about what patients expect but also in providing a data set against which those expectations can be measured. Another example is when participants are asked about their 'Open Window' experience, the response they give is important for supporting, clarifying and explaining the 'Open Window' questionnaire and understanding their psychological response.

The issue of the combined confirmatory and exploratory nature of the qualitative data was a key consideration in deciding on the most appropriate data analysis procedure. Other factors that influenced this decision were the semi-structured design of the interviews in which pre-determined issues for discussion were documented in the interview guide and also the volume of data that resulted from this process. Fifteen participants were interviewed on three separate occasions from each of the four groups. This resulted in 180 interviews for transcribing and analysis.

Computer assisted qualitative data analysis software known as NVivo 7 (Bazeley 2007) was used to manage and support the qualitative data. This package facilitated the management and organization of a large amount of data in an exploratory and transparent manner. It allows the production of a clear audit trail of the analytical processes and interpretations of data that I made during analysis. An explanation of how NVivo 7 operates and was used is being provided in order to demonstrate how it facilitates the analysis of qualitative data within a descriptive design and using template analysis as a framework. NVivo stores data in 'nodes' which represent themes and categories. The nodes are populated by data imported from sources, which in this study are word documents containing transcribed interviews. These interviews from each participant are labeled the same as the questionnaires and imported into 4 folders corresponding with the 4 groups that emerged from the randomization process. Five types of nodes are available to analyse the data, these include; Free Nodes, Tree Nodes, Case Nodes, Relationship Nodes and Matrix Nodes. Free nodes are used to house the broad themes or *a priori* themes. Tree nodes are similar to free nodes

in that they contain themes; however they have additional properties of being able to be grouped into associated themes. They can also have ‘children’ which represent a hierarchy within the groups. Case nodes are used to generate case files that contain all data related to each participant. This is linked physically to relevant demographic details and quantitative survey data, for example, data from the expectations survey questionnaire was imported from SPSS into NVivo 7 in order to link these data with qualitative data relating to participant expectations. It is particularly useful in this study because it allows the qualitative data from each of the four groups to be analysed separately. This is essential in a mixed methods study of this design (embedded) because the qualitative data can be used to support and explain outcomes from the quantitative data. Relationship nodes are used to record and illustrate relationships between or across themes; for example, in this study it was evident from the qualitative data that communication issues and in particular, trust, were important to participants in relation to control issues. Matrix nodes are used to link the different nodes with cases and demographics. They are also used to illustrate how often a particular code may have been referenced. This is called quantitised data and is defined by Teddlie and Tashakkori (2003, 9) as a process where “collected qualitative data types are converted into numerical codes that can be statistically analysed”. Tables produced by NVivo 7 can be exported to Excel where further statistical analysis and production of graphs, tables or charts can be conducted. Examples of these graphs, which illustrate qualitative data in percentages, are seen throughout chapter 6. This type of analysis is thought to enhance the interpretation of mixed methods results (Onwuegbuzie and Teddlie 2002).

#### *5.10.2.1 Template Analysis*

Template analysis was considered to be the most appropriate framework for data analysis in this study. This framework includes a number of techniques for organising and analysing textual data thematically and, according to King (2004), it can be used within many epistemological positions. Other approaches to data

analysis such as grounded theory could also be used as a framework for data analysis; however, this is not a grounded theory study and the specific procedures identified by Strauss and Corbin (1990) for data collection and analysis were not considered appropriate due to the structure and content of the interviews and the considerable amount of data collected (a total of 180 interviews were conducted). Interpretative approaches to data analysis commonly used in phenomenological studies could also be considered appropriate to this study. However, although similar in practice to template analysis (King 2004), interpretive approaches tend to analyse each interview to a greater depth than template analysis. Template analysis requires the researcher to identify themes from the data in advance of analysis. These are also known as '*a priori*' themes and indicate that the researcher assumes that particular relevant issues relating to the topic being studied are contained within the data. King (2004, 2006) identifies the main benefit of using '*a priori*' themes is that it accelerates the initial coding phase of analysis and therefore allows the researcher to manage larger data sets as produced in this study. This was very important for this study as a very large data set was generated from the interviews; however, another key feature of template analysis was that it facilitated the production of a summary of patients' perceptions of 'Open Window' and how this influenced their experience of having a stem cell or bone marrow transplant. This was the main purpose of using a descriptive qualitative design as described by Sandelowski (2000b). A second key advantage of using template analysis in this study is that the main themes are already identified in the interview guide and the interview process involved moving from one theme to another. The delineation between each theme was clear in the transcriptions, therefore, initial *a priori* themes reflected the issues listed in the interview guide.

Although template analysis allowed me to focus on issues relevant to the research questions, possible disadvantages of identifying *a priori* themes were that I would overlook relevant information because it did not relate directly to the themes or the data may not actually fit with the *a priori* themes identified. King



(2006) suggests that in order to prevent this, the researcher should consider *a priori* themes as tentative and keep them to a minimum when developing the initial template. This would reduce the risk of overlooking relevant data and encourage the development of themes where appropriate.

King (2004, 2006) describes the stages of the template analysis framework as defining *a priori* themes, followed by transcription of the interviews and reading to become very familiar with the content. The next stage involves conducting initial coding of the data, attaching it to an *a priori* theme, if appropriate, or identifying a new one if necessary. At any phase of template analysis, themes that already exist can be modified or deleted and data can be moved across themes or within more than one theme if necessary.

Throughout this process I was guided primarily by the research questions and aims of the study. However, I found that the interpretive process was enhanced by consistently reading individual transcripts. This provided additional meaning to the data by contextualising it and also ensuring that I did not ignore data that were not common across all the transcriptions. This process required that I remain open to all the data and reflexivity was a key component of achieving this successfully. King (2006) suggests that the techniques used in template analysis encourage reflexivity as the development of the templates and decisions relating to identifying and coding themes need to be explicit. These will be presented and discussed in chapter 6.

Identifying *a priori* themes that were directly linked with the interview structure and content and also with the research questions and aims of the study was instrumental in facilitating the integration of the quantitative and qualitative findings. According to Creswell (2006, personal communication), where relevant, for example in studies where data are collected concurrently, quantitative and qualitative findings should be presented in an integrated way in order to meet the aims of the study and address the research questions. For

comparative purposes, and in keeping with the clinical trial design of the study, qualitative data from each study group were analysed separately.

## **5.11 Quality initiatives**

In addition to receiving ethical approval from the hospital ethics committee to conduct this study, it was also necessary to receive permission from the hospital's 'Patient Advocacy Committee'. This Committee was established as a quality initiative and its purpose is to direct, promote and develop hospital programmes to increase patient satisfaction and empowerment. Membership includes hospital board members, local community representatives, the hospital's chief executive officer, deputy chief executive officer, director of nursing, risk manager, complaints manager, quality initiative manager and accreditation manager. A copy of the study protocol was submitted to this committee and following consideration by the committee, permission to proceed with the study was granted (Appendix 12).

### **5.11.1 Study Documentation**

The development and finalisation of the study documentation (patient information and consent form) involved a number of stages. The first was giving a draft of the documents to the clinical nurse managers, and members of the psycho-oncology team (senior clinical psychologist and psychiatrist) and academic colleagues to review. The purpose of the review was to reveal any problems with sequencing, detail and wording of the content. They were also asked to comment on their overall understanding of the study based on the documents alone. However, this may have been biased due to their prior knowledge of the 'Open Window' project, therefore, after the first review I submitted the documents to The National Adult Literacy Agency (NALA). Under its project called 'Plain English' NALA offers organisations the service of editing documents with the focus on writing style and the use of plain English and language. The aim is to produce documents that communicate effectively

with all members of society and ensure that the message is clear and understood by all who read it.

Following the editing process by NALA, people who had no connection with the research project or the health care profession were asked to review the documents. They were asked to comment in terms of clarity and overall understanding of the concept of 'Open Window' and the study process. Feedback from this stage of the review was positive with no additional suggestions offered.

Before the final draft of the documents was printed, the cultural diversity officer employed at the research site was asked to review them. Clarity and terminology were the main focus of this review with a particular reference to the meaning of terms and phrases included. The cultural diversity officer gave positive feedback and did not offer additional changes or suggestions.

### **5.12 Establishing trustworthiness**

Trustworthiness is a term used to denote rigor in qualitative research. It is concerned with ensuring that the research process is explicit and, therefore, inspires confidence in the reader. It comprises four criteria including credibility, dependability, auditability and fittingness (Sandelowski 1986). Credibility refers to confidence in the truth of the data and the researcher needs to demonstrate this by taking certain steps throughout the research process. Dependability refers to the stability of the data and its establishment, and is inextricably linked with the existence of credibility. The third component is auditability and according to Streubert Speziale and Rinaldi Carpenter (2003) it is a process criterion by which the researcher uses an audit trail consisting of examples of coded data, lists of codes, communications, and rationale to document and support the decisions made in relation to the research process. Fittingness refers to the potential for the findings to be relevant or meaningful in other contexts unrelated to the study; therefore, this is established by others and not the researcher. However, it

implies a responsibility for the researcher to disseminate the process of the study and findings using relevant media.

Credibility was a difficulty in this study because it was not feasible to return transcripts to participants for confirmation (member checking), as they were possibly physically and psychologically unwell as a result of having a life threatening illness and the intense treatment required for stem cell transplantation. Koch and Harrington (1998) and Sandelowski (1998) question the benefit of returning to the respondents to check data because it will be transcribed directly from a digital recorder which will establish verbal accuracy. Also, respondents may not recognise their individual contribution to the findings as they will be presented as themes. For this reason, in order to establish credibility in other ways, when re-interviewing participants I referred back to what they had said in the previous interview in relation to each issue discussed. The purpose of this was to remind patients of what they had said so that they had a base from which to determine their current views on the issue and discuss any changes. Credibility is demonstrated also by including a transcript in the final report (Appendix 18).

An audit trail was used throughout this study to provide rationale relating to the study design and sampling; however, this detail is particularly important for supporting and clarifying the qualitative part of the study, that is, the interview type and content, the number of participants being interviewed, data collection points, analysis and presentation. I did not use peer checking as a means of demonstrating credibility because I agree with numerous authors (Geanellos 1998, Cutcliff and McKenna 1999, King 2004, 2006) who suggest that a single piece of datum can be interpreted in many different ways, depending on the researchers' frame of reference or profession. This is in keeping with the philosophy of pragmatism underpinning mixed methods research as discussed in chapter three. This relates to the dynamic nature of truth that is always

provisional, because it changes and represents only one reality in time (Burke Johnson and Onwuegbuzie 2004).

According to Sandelowski (1986) fittingness occurs when a study has the ability to transfer or 'fit' into similar external contexts or situations and its findings are regarded by others as meaningful and applicable. It is clear from presenting the 'Open Window' Project at international medical and art conferences, that it is regarded as meaningful and applicable, as a number of other health care institutes, for example, in Italy, are now installing 'Open Window' in their bone marrow transplant unit and wish to conduct similar research. Other centres, for example in the United States, have expressed an interest in installing 'Open Window' in their Care of the Older Person Units and also intend to conduct evaluative research. It is possible to suggest that although there is limited evidence of its effectiveness in any context, there appears to be a belief that 'Open Window' and its evaluation have enormous potential in addressing environmental and psychological needs of patients in many clinical contexts.

### **5.13 Summary**

This chapter includes a detailed account of the research methods used in relation to identifying the study population, sampling, recruitment, consent, randomisation, data collection, and data analysis. Running throughout the content is detail relating to the relevant considerations and decisions surrounding the choice of each method. Preparation of other health care staff involved in the study, for example transplant co-ordinators and ward managers, included regular information sessions and trouble shooting.

Two pilot studies were conducted in order to test the procedures in place for recruitment and data collection and identify any problems patients and the researcher may have had with the questionnaires and interviews.

The methods used for the study are based on the philosophy of mixed methods research and the ultimate aim of this embedded, mixed methods design is to present the quantitative and qualitative findings in an integrated way that acknowledges the differences, but also the relevance and understanding that using different research views has in evaluative research.

#### **5.14 Conclusion**

Preparation and ongoing support of the transplant co-ordinators involved in recruiting participants and the ward managers who would be required to co-operate with the randomisation procedures, proved to be a key aspect of ensuring recruitment, randomisation and data collection ran smoothly. The positive relationship that I built up over time with the transplant co-ordinators, ward managers and nursing staff appeared to stimulate their interest in 'Open Window' and the research being conducted to evaluate it.

The pilot studies highlighted the need for flexibility in the study and demonstrated that this was possible while still adhering to the principles of randomised controlled trials. The pilot studies were very useful in ensuring that the systems and procedures in place for recruitment, randomisation and data collection were feasible and ran smoothly. Issues relating to the use of the questionnaires or conducting interviews did not arise for either patients or the researcher.

## Chapter 6: Results

### 6.1 Introduction

A detailed account of the qualitative findings is presented at the outset of this chapter. These data represent a comprehensive view of the participants' experiences of 'Open Window' and undergoing a stem cell or bone marrow transplant. Due to the absence of this type of information in the literature, these aspects of this study provide a unique contribution to knowledge in this area. It should be noted that due to the mixed methods design of this study, further relevant qualitative data will be presented in an integrated manner with the findings from the questionnaires.

The statistical results from the four questionnaires are then presented. The results start with an outline of the demographic data and are then presented according to each questionnaire. The expectations questionnaire is presented first, followed by the 'Open Window' survey questionnaire and finally the psychometric tools, the HADS and the DT. In accordance with the embedded nature of this mixed methods research design, the findings from the qualitative data are incorporated with the quantitative data where appropriate but a section outlining the overall findings is also provided and supported by relevant appendices.

### 6.2 Qualitative Results

#### 6.2.1 Introduction

As discussed in the previous chapter, qualitative data analysis was conducted using template analysis as the framework and NVivo 7 to store and manage the data. The first phase of analysis was the identification of *a priori* themes, which formed the initial template (Appendix 19). This template was then used in a continuous process of development by applying this template to each transcript until the full data set had been coded (free nodes). I used the final template as a

means of providing an account of my interpretation of the data and the development of a list of sub themes (tree nodes). Thirty three sub themes were identified (Appendix 20 & 20a). Phase 2 of the analysis entailed grouping the relevant sub themes with the main themes identified on the final template, some of which were relevant to more than one theme and were, therefore, listed under two or more themes (Appendix 21 & 21a). NVivo relates this to forming 'children' of the free node or parent node. Phase 3 analysis involved re-organising children with parents and in many cases the development of additional levels of sub themes or nodes called grandchildren and great grandchildren. The purpose of this stage of analysis is to build a picture of the outcome of the data in a logical and transparent manner. This is evident in the layered and/or hierarchical structure of the sub-themes or nodes and required running a number of queries using NVivo tools such as word searches and matrices. The different levels of analysis are apparent in appendix 22 (incl. 22a – 22e). Each phase of analysis and sub theme has a memo attached, which outlines its relevance and links to other themes and sub-themes. These are indicated by the green label. Each memo has been imported into a word document and provides a transparent and logical presentation to the analysis process and outcomes (Appendix 23). Stage 4 of the analysis involved running a small number of perspective queries in order to support and enhance the interpretation and understanding of the data. These queries arose from my own feeling from listening to data and reading interviews, that participants in the allogeneic group commented more frequently on the environment, its prison-like characteristics and perceived control of their lives. The perspectives tool allowed me to look at the results according to group and it emerged that there was, in fact, little or no difference between the groups in relation to their interpretation and feelings about their environment, or control issues (Appendix 24).

The outcome of this process was the production of the final template containing the main themes (Appendix 16). This template comprised five *a priori* themes, which linked directly with the topics for discussion listed in the semi-structured



interview guide. Following further exploration of the transcribed interviews, one new theme which I named ‘self and others’ emerged from the data and was included as one of the main themes (figure 6.1). The topics included in the semi-structured interviews related specifically to exploring participants’ personal accounts of issues relating to primary outcomes of the study, for example, depression, anxiety and distress are caused mainly by perceived loss of control and stress; expectations are included in the interviews in order to provide a baseline for the expectations questionnaire; and the environment as a means of determining participants’ views on its aesthetics, function and how it made them feel (section 4.9.4). These data were important in providing explanations related to the primary and secondary outcomes of the study; however, an insight into participants’ overall experiences of living with a life threatening illness and undergoing stem cell or bone marrow transplantation also emerged from the data. Subjective information relating to the interview topics of the environment, expectations, control, and stress provided a broader picture than just relating to ‘Open Window’. This is particularly evident in the emergence of the unexpected theme ‘Self and Others’.

Figure 6.1: Final Template (Main Themes)

<b>Final Template (Main Themes)</b>
1. Control (a priori)
2. Environment (a priori)
3. Expectations (a priori)
4. ‘Open Window’ (a priori)
5. Stress (a priori)
6. Self and Others (new theme)

### 6.2.2 Control

The first *a priori* theme was control and relates to comments participants made about their perceptions of control over their lives or situation. They talked about the factors that influenced their perception of having either complete control, some control or no control. These factors included communication issues, knowledge and personality and although some expressed feelings of frustration at not having control, most expressed positive views and an expectation of having control in the future.

Participants who perceived that they had control over their lives were quite emphatic about it. They were confident that they continued to make decisions and be part of activity related to their treatment, daily life in the Denis Burkitt Unit and plans for their discharge and recovery. This perception of control seemed to centre on seeking and receiving appropriate information from relevant people but also related to how they perceived themselves and their personalities. In other words, if they always had control in their lives, having a life threatening illness was not a reason to change.

When asked if they felt they had control over their lives, some participants commented that they had control, whereas others said they had some but not total. Retaining control centred on keeping informed of the treatment and recovery process and expectations. This meant persistently asking questions of the medical/nursing staff and believing that the responses they received were informed and genuine. Other participants felt that they retained control by having a positive mental attitude and complying fully with treatment even though they did not always understand the purpose of the medication they were on. Participants also seemed to feel a sense of control over the decision to have a transplant; ultimately they felt that this had been their decision and were, therefore, prepared for the consequences and aware of the importance of complying with treatment. The need to be in the right place in order to recover was evident as a way of retaining some sense of control.

- “I’ve constantly asked questions, I’ve constantly look for information ... the reason is that I want to know what’s going on because then I’m not surprised when something happens”

[Documents\Allo Control Group B\T1\AL035CT1](#)

Participants who perceived that they did not have any control did not regard this in negative terms because they did not expect to be able to control something they knew nothing about or did not understand, and appeared to accept that. They were happy to leave this to the doctors and nurses as the ‘experts’ and professionals.

- “I can go with it as well because I can accept that they are professionals and they know exactly what they’re doing and therefore without hesitation I comply to everything that they ask me to and that’s been my way since, since we started this back in October what they say I do, without question because they are the bosses.”

[Documents\Allo Intervention Group A\T1\AI027IntT1](#)

A small number of participants described feelings of frustration and talked about their desire to retain control as they recovered and got back to their ‘normal’ lives. Some talked about feeling depressed about not having control, saying that it made them feel insignificant as an individual. They lost their ‘role’ in the family and could not contribute in a meaningful way. However, most saw this as a temporary measure and looked forward positively to regaining control.

Although most participants were optimistic about regaining control of their lives in stages as they recovered, some felt that regardless of how well they recovered or how normal their lives were, the possibility of the cancer returning would always be in their minds to a greater or lesser degree. They felt that this meant they would never have complete control of their lives in the way they did before they became ill.

Communication with staff was described by most participants in positive terms, for example, staff were helpful, kind, informative and respectful. Some participants described trusting the staff in a way that suggested it was essential in giving the participants confidence in the treatment and recovery process. This appeared to contribute to their perception of whether they had any control over their situation. Trusting the staff meant that even if they perceived that they didn't have control, it did not cause negative feelings as they trusted others to have the control. When participants commented that they did not trust the staff, although this did not happen often, it seemed to reduce their confidence in terms of treatment and clearly made them feel more anxious.

- “I feel very confident that people know what they're at but I don't feel very confident in some, I know we all have different personalities but they have to be able to deal with different people. I would not feel very confident when that lady coming in to treat me now that's being honest with you. She just felt I needed it [morphine] without finding out my information you know and it made me feel under pressure. My guard came up then because I live my own life and I'm very independent and I just said 'this woman never went through what I'm going through, she has only studied it, it's completely different'”

Documents\Allo Intervention Group A\T1\A1038\ntT1

### 6.2.3 Environment

The second *a priori* theme was 'environment' and encompasses all comments that participants made in relation to their immediate surroundings and the wider environs of the Denis Burkitt Unit. When asked for their views of the environment, participant responses generally related to practical or aesthetic issues. Some spoke positively, but many highlighted negative aspects of the room. Words such as, clinical, clean, functional, bright, airy, and nice were used

when providing positive descriptions. Words like dark, small, and prison-like were used in negative descriptions. Participants used the term 'prison-like' because they could not go outside for fresh air, the use of double doors, the ante chamber before entering the room and limited visitors. These features resulted in feelings of confinement and physical isolation. However, many of these references were followed by comments that indicated that participants also understood why they were there, the reasons for the restrictions and, if given the choice, would not want to be anywhere else because that is where they needed to be in order to get better. Some participants regarded the visiting restrictions, the intense cleaning regimen and the air lock as reassuring and it made them feel safe from infection, which gave them confidence in the treatment and care they were receiving. Other descriptions included 'hospital like' or 'grand' and tended to be used when participants did not have particularly strong feelings about their environment one way or the other.

- “My feeling in the room is that the room is protecting me so I you know so they said for instance on the ward you know, you may walk up and down the corridor ward with a face mask on, and one big reason I haven't done that is I thought this room is set up a hundred percent care for me whereas once you go past that second door there you are less protected, you can bump in to someone and, exchange germs and all the rest of it”.

Documents\Allo Intervention Group A\T4\AL042IntT4

When asked what aspects of their environment they would change if they had the choice, participants referred to practical features, such as, the shower, having the TV lower and a bigger screen, lack of storage and the size of the room. Aesthetic aspects of the room such as the need for more colour and the absence of décor were referred to with much the same frequency as practical issues. Interestingly, when asked if their views of their environment had changed six months after the

transplant, practically all commented that their views had not changed and they consciously did not think about the Denis Burkitt Unit.

#### 6.2.4 Expectations

The third *a priori* theme was ‘expectations’, which contains responses from participants when asked specifically about their expectations of their physical and psychological response to treatment, recovery and their future. Participants generally felt that they knew what to expect in relation to how they might respond physically to the treatment. Nausea, vomiting, fatigue and diarrhoea were top of their list but many also felt that they may not get these symptoms too badly and based this on their past experiences of chemotherapy. Some were confident that with medication they would be able to cope with the physical symptoms. The high risk of infection and/or mucosytis also caused some anxiety but participants generally felt that if they complied with treatment and stayed in their room with limited visitors, they would be ok. There was a high level of confidence that the nursing and medical staff would be able to anticipate their needs or help them if they needed it.

- “I would feel very blessed if I respond to this regime as I did to the last which was miraculous... I got away lightly so if that happens this time, I won’t be as ill as I could be”

[Documents\Allo Control Group B\T1\AI028CT1](#)

- “They say I’ll be quite sick but I don’t mind, it will be the usual things that you get from prior chemos, I mean I’ve had five doses of chemo already so I’m pretty used to the side effects”

[Documents\Allo Control Group B\T1\AL039CT1](#)

Participants’ expectations in relation to their psychological response to treatment suggest that they were generally quite confident that they would be able to cope

well psychologically with the intensity of the treatment and recovery. As with the physical expectations, this was based on their past experiences of being in hospital and being very ill for long periods of time. Most referred to the presence of immediate family in their room as being the most helpful in helping them to deal psychologically with the experience of having a transplant. Others felt that positive thinking and sleep were also very important.

- Q: “What do you think it’s going to be like?”

A: Psychologically a bit stressful but I’m quite strong in mind so. I’m going to work at getting through it and get out the other side and that’s my focus”.

[Documents\Allo Control Group B\T1\A1025CT1](#)

When asked about their expectations of their future, participants were generally very optimistic and tended not to plan too far ahead. The future did not include any grand plans of dramatic changes in lifestyle, many responded that other than perhaps taking more holidays, and spending more time with family, their main aim was to return to ‘normal life’.

- “When I get out of here I will try to get back as soon as I can to work and I will enjoy every day and I will try not to annoy my girlfriend too much and maybe in a year’s time she will, eh she will respond favourably to me popping the question”

[Documents\Allo Control Group B\T1\A1019CT1](#)

- Q “Do you have any specific plans made for when you get out, like is there anything you know like, you know the way people always say ‘oh when this is over now I’m gonna do this I’m gonna do that’ do you have any plans?”

A: I want to do my garden”

[Documents\Allo Control Group B\T1\A1021CT1](#)

Participants indicated that the only way they had changed or that the experience had the potential to alter their future lives was in two ways. The first was that they felt they prioritized differently as a result of their experience, things that would have bothered them in the past, what they referred to as ‘minor’ things’ would no longer affect them. The second change to occur was participants’ surprise at how their own personal strength and ability to endure difficulties.

- “I’ll be less bothered by things, you know, all little things that normal teenagers would get bogged down about, I wouldn’t care about that anymore”

[Documents\Allo Control Group B\T1\A1018CT1](#)

When participants were discharged and as treatment and recovery progressed, many commented on the intense debilitating fatigue they experienced and for some, the worry about the possibility and extent of developing graft versus host disease caused anxiety.

However, they also talked about the factors or short term goals that they regarded as milestones in their recovery and return to ‘normal life’. Walking, completing household chores, and gardening seemed to be important achievements. For some, returning to driving was important as it gave them independence and control over certain aspects of their lives.

#### 6.2.5 ‘Open Window

The fourth *a priori* theme was ‘Open Window’ and refers to participants’ comments and descriptions of their overall experience of it. They were asked to describe their overall experience of ‘Open Window’. This did not seem to be a difficult request and they talked freely about their likes, dislikes in relation to it and how it made them feel. Their experiences can best be classified firstly in terms of ‘appreciation of art’ and secondly as comments on how it made them feel which centered on distraction and connection with the outside world



(Appendix 25). Participants demonstrated appreciation of art by commenting on the importance of positive images, colour and life. When they did not like a particular image, they were always very clear about why they did not like it and often this was because they saw no meaning in it or it seemed unrelated to them in any way. Other reasons included the images being too dark or abstract. However, regardless of whether they liked it or not, they spent time expressing their opinion.

• Q: The tree, the ‘Smoke Tree’, you said you didn’t like that one or that was the one you least liked?

A: It’s just so grey ... Grey, grey, grey, we’ve enough of grey

Documents\Auto Intervention Group C\T4\Au013 Int T4

When asked how ‘Open Window’ made them feel some participants used the words ‘distraction’, ‘interesting’ or ‘something else to look at’. Others used terms such as relaxing and reflective. It became clear that some participants regarded it as a distraction while others felt it provided connection with the outside world and some experienced the value of both (Appendix 25). Certain images on ‘Open Window’ helped participants to relax or just reflect on life and their situation.

• “I thought the whole thing as regards getting the pictures was just amazing, because, it was my contact to the outside world as regards like an event that was happening; that I could never access”

Documents\Allo Intervention Group A\T4\A1014IntT4

For some it caused them to imagine being part of the scenes that they viewed and they valued its ability to let them be ‘somewhere else’ other than their room and even think about something else other than their illness. Participants did not generally use the term ‘connection’ but they talked about the importance of finding personal meaning in the images they saw. Although many participants

chose to view personal images or images of familiar places, many also found meaning in images unrelated to them personally. An example of this is how one artist's images of mountainous scenes in Iceland reminded many participants of the Burren in County Clare or the abstract video piece of New York was particularly interesting to a patient who planned to visit there when she recovered. She said she always wondered if she would recognise places when she was there in reality. Those that looked at personal images were happy to see everyday things like the new car that they had not seen or the dog sitting outside the back door. Some were pleased to see from the images that things had not changed much at home and others were just excited to see what images their family thought they would like to see.

Due to the nature of the treatment and the intense physical symptoms experienced by participants, many commented that they were too sick to be interested in anything. This included interacting with family or staff, reading, watching TV or viewing 'Open Window'.

Participants generally felt that 'Open Window' did not have a long term effect as they consciously tried not to think about their experiences in the Denis Burkitt Unit (Appendix 26). A small number (n=6) of participants commented on how they felt they were more conscious of visual arts, and how scenes of nature in particular reminded them of 'Open Window'. Even though there did not seem to be a long term effect as a result of experiencing 'Open Window', most participants retained positive memories of it.

- "Q. As a result of your experience with 'Open Window', are you more aware of art?

A: I'd be more aware yeah... even just advertising on a bus or a truck going by like it just catches your eye and you'd remember things."

Documents\Auto Intervention Group C\T7\Au017\IntT7

### 6.2.6 Stress

The fifth *a priori* theme was ‘stress’ and includes responses from participants when asked if they felt they experienced stress and how they dealt with it. The majority of participants said they experienced stress, with the main causes of stress related to the side effects of treatment, such as appearance, or pain or diarrhoea. However the stress reported was low level, acute and/or episodic.

- “ Yes I have been stressed, like anybody that’s is going through this or anybody that’s going into hospital or going through chemo therapy and you’re losing your hair and, you know, you see people that lost their hair, but the day they shave your head and you stand up and you look at yourself in the mirror you know, it’s just stunning! It is like I went home then and I was really ok about it but you stand at the kitchen sink and the next thing you look in the mirror and you see this bald face”

[Documents\Allo Control Group B\T1\AL035CT1](#)

Participants who said they did not experience stress were quite emphatic about it. They said things had gone better than they expected or they did not generally experience stress anyway in their lives. Most took the pragmatic approach to their situation and regarded it as something they had to do in order to get better.

- “No I wouldn’t I wouldn’t feel stressed at all and I would maybe the odd time you’ve, I wouldn’t be a stressful person though anyway”

[Documents\Allo Control Group B\T4\AL040CT4](#)

- “I don’t have any stress, even when they told me, I mean, even when they told me the diagnosis, I wasn’t very shocked but I just want to know what kind of cancer I have, I mean, how they would treat with that and if there any chance to get remission from it”

[Documents\Allo Control Group B\T1\AI011 C T1](#)

- “I don’t get stressed really, I just go with the flow. I don’t want to know what is happening in 2 weeks time, I just want to know about tomorrow”

[Documents\Allo Intervention Group A\T1\AI026IntT1](#)

Participants talked about how they experienced stress by being angry or anxious. Some did not feel that being stressed was a major problem and either dealt with it or ignored it. The level or severity in which they experienced it was influenced by their previous exposure and reactions to stress. Some commented that stress was never an issue, it did not feature in their lives. It was clear that some were more aware of it than others and also people addressed it in varying ways. Even though the majority of participants in this study experienced stress it seemed to be acute episodic stress that was reduced when symptoms were relieved or they started responding to treatment with blood counts going up. Chronic stress was not described by any of the participants.

Participants identified numerous ways in which they dealt with stress. These included medication, music, being irritable. Others distracted themselves by reading, writing or going on their computer. Many said they dealt with it by just getting on with things and attributed this to their personality. Others used various support structures that they found helpful, for example, having family present or for a small number of participants, prayer was helpful. Family and friends were the most common source of support in dealing with stress. They

talked openly with family about their illness and side effects of medication. They obviously trusted family to understand when and why they did not want to talk at times and also know when they were ready and able to be more independent. A number of participants commented that the way they dealt with stress reflected their personality. They took a pragmatic approach and just got on with things or they did not think about it at all.

- “I listen to a lot of music but I don’t probably deal with stress very well, I go in to a bad mood for a couple of days and bark at people. I also find it difficult being around people because I’m irritating them but they are the answer to my stress! Talking about things really helps”

[Documents\Allo Control Group B\T1\AI019CT1](#)

#### 6.2.7 Self and Others

The sixth theme, which is not *a priori*, is called ‘self and others’ and emerged unexpectedly from the data as a main theme because participants referred frequently to things they had learned about themselves as a result of going through the experience of being diagnosed with and receiving treatment for a life threatening illness. They also talked about how relationships with family and friends had changed during this time. This theme was somewhat of a surprise in that it was very positive; participants did not seem to feel sorry for themselves and at times talked about the positive or good things to come out of their illness and experience and they were happy about that.

- “I’m probably more honest with people and more understanding of what’s important and that kind of stuff”

[Documents\Allo Control Group B\T1\AI019CT1](#)

Some participants felt that they had not learned anything about themselves or that they had not changed in any way and that their response to their experience

reflected their personality and the way they would always have dealt with things. Most, however, expressed the view that they had learned things about themselves and almost all said that they had changed in some way.

- “I think I’m a better person than I was before.

Q: What makes you say that?

A: It’s experience more than a lot of other people have had.

Q: How do you feel that makes you a better person?

A: I wouldn’t be as selfish as normal teenagers, I feel more mature than others because of what I’ve been through”

[Documents\Allo Control Group B\T7\A\1018CT7](#)

Participants expressed surprise at how much inner strength they had; this related to psychological and emotional strength particularly. They liked this and it may have contributed to their sense of control and also their confidence in thinking positively about their situation. Some participants said they learned about this from friends and family but many said they felt it themselves. It is clear that personal growth is a feature of this experience. Many participants said that as a result of having a life threatening illness, they now prioritised things differently in their lives. They did not get as stressed or irritated over what they perceived to be minor issues and at times felt irritated when friends and family seemed anxious over something trivial. When asked if they felt this alienated them from others or made them feel different in any way, the participants responded that it did not or if it did, they felt it did not affect their relationships with others.

- “You just realise how strong your character actually is eh, how positive you are, you know you find out how positive you are and how you actually cope as a patient which I was never used to. I went from being like a completely normal thirty one year old playing football on Saturday to a leukaemia patient on Wednesday you know that kind of a way. Life just went from one extreme to the other! I learned the importance of all my friends and the

importance of my family. I've learned that they are even more important than I actually thought before all this"

[Documents\Allo Intervention Group A\T4\AI014IntT4](#)

- "Generally speaking now I do kind of see life a little bit differently. I suppose before all this I would have found things a major problem, but they're not problems now. I can deal with things much better, I'm just a bit more philosophical about what is a major problem.

[Documents\Allo Control Group B\T1\AI025CT1](#)

The relationship that participants had with family was consistently reported as positive and a key source of strength and support. Many reported that their relationships had grown and become stronger and they commented on this very positive aspect of their difficult situation. The physical presence of family in their room was extremely important and contact by phone or email was also reassuring. Some participants felt that being diagnosed with a life threatening illness made them realise who their real friends were and expressed surprise that some friends were not as supportive as they thought they might have been. On the positive side they felt that many new friendships were formed so social relationships were also generally perceived positively. However, it was clear that close family relationships were the most important, supportive and reassuring; this included parents, children, brothers, and sisters and partners. Outside of this circle, relationships were important but not essential.

- "I'm a different person altogether now, a scratch on my car is a scratch on the car you know I couldn't care less it's easy come easy go!

Q: Alright ok, well how do you prioritise what's important now?

A: Family and friends!"

[Documents\Allo Control Group B\T1\AL034CT1](#)

- “I need them more than I used to and I’m probably more honest with them, maybe they’re more honest with me”

[Documents\Allo Control Group B\T1\A1019CT1](#)

Family was identified as the main and most important source of support for the participants. This is where the close relationships were evident and participants sometimes became emotional when talking about them. They valued the way in which the family came together and coped at home and were a constant presence in hospital. They also seemed to learn the value of talking about the situation as a family and not hiding things. Other sources of support included friends, and the medical/nursing staff in the Denis Burkitt Unit and the Day ward.

- “When you feel that low you, it’s always your mum (laughter) you want! If things are bad I ring my mum and it must drive her insane ...when I feel really bad then it’s mum that I cry to”

[Documents\Allo Control Group B\T1\A1020CT1](#)

- “Even the whole nausea and vomiting it didn’t bother me at all with the family members here. You know that kind of way because they were, they were there for me and they were quite helpful you know just sort of, whether they were holding my hair back or just being there... I just felt relaxed with them because of who they were”

[Documents\Allo Control Group B\T4\A1025CT4](#)

## **6.3 Quantitative Data**

### 6.3.1 Statistical Tests

Statistical analysis was conducted using SPSS 15.0 for Windows. These included means, frequencies, crosstabulations and chi square for independence for the ‘Open Window’ and Expectations questionnaires where appropriate and repeated measures ANOVA with between-subjects factors for the HADS and DT.



## 6.4 Results

### 6.4.1 Demographic findings

Up to the point in the study being presented in this thesis document, a total of 68 participants had been recruited to the study, 36 were in the intervention group and 32 in the control group (table 6.1). It is understood that even though some comments and explanation are provided in relation to the results, they are entirely questionable due to small numbers. They are included in order to suggest potential trends and possible effects of ‘Open Window’ that may be evident and statistically significant in the main study.

Table 6.1 Demographic Data

			Frequency	Percent	Valid Percent	Cumulative Percent
<b>Number of Participants</b>	Total	Intervention	36	52.9	52.9	52.9
		Control	32	47.1	47.1	100.0
	Total		68	100.0	100.0	
	Autologous Group	Intervention	14	48.3	48.3	48.3
		Control	15	51.7	51.7	100.0
Total		29	100.0	100.0		
Allogeneic Group	Intervention	22	56.4	56.4	56.4	
	Control	17	43.6	43.6	100.0	
	Total		39	100.0	100.0	
<b>Age</b>	Autologous Group	18-25				
		26-34	4	13.8	13.8	13.8
		35-49	6	20.7	20.7	34.5
		50-69	19	65.5	65.5	100.0
		Total		29	100.0	100.0
	Allogeneic Group	18-25	5	12.8	12.8	12.8
		26-34	7	17.9	17.9	30.8
		35-49	15	38.5	38.5	69.2
		50-69	12	30.8	30.8	100.0
		Total		39	100.0	100.0
<b>Gender</b>	Autologous Group	Male	18	62.1	62.1	62.1
		Female	11	37.9	37.9	100.0
		Total		29	100.0	100.0
	Allogeneic Group	Male	27	69.2	69.2	69.2
		Female	12	30.8	30.8	100
		Total		39	100.0	100.0
<b>Education</b>	Autologous Group	Secondary/senior Certificate/Diploma	17	58.6	58.6	58.6
		Graduate	7	24.2	24.2	82.8
		Post Graduate	4	13.8	13.8	96.6
			1	3.4	3.4	100.0
		Total		29	100.0	100.0
	Allogeneic Group	Secondary/senior Certificate/Diploma	20	51.3	51.3	51.3
		Graduate	4	10.3	10.3	61.5
		Post Graduate	11	28/2	28/2	89.7
			4	10.3	10.3	100.0
		Total		39	100.0	100.0

For the purpose of clarity and to present the demographic profile of the stratified groups, that is, participants who underwent allogeneic and autologous transplantation data are illustrated separately in table 6.1. A total of 29 participants who had undergone autologous transplantation were recruited to the study; this represents one third of the total population, the remaining 73 were ineligible as they received their transplant in the Haematology/Oncology Day Centre and then returned to various other hospitals. Thirty-nine people who had undergone allogeneic transplantation were recruited, this represents the entire population (with the exception of 2 patients who declined to take part in the study) as all allogeneic transplants took place in the Denis Burkitt Unit. Of the 29 who had an autologous transplant, 14 (48.3%) were randomised to the intervention group and 15 (51.7%) to the control group. In the Allogeneic transplant group 22 (56.4%) were randomised to the intervention group and 17 (43.6%) to the control group (table 6.1)

The majority (65.5%, n=19) of the participants who had an autologous transplant were in the 50-69 age group with 20.7% (n=6) in the 35-49 group and 13.8% (n=4) in the 26-34 group. No participants were in the 18-25 age group, this reflects the normal age distribution in patients who are treated for haematological malignancies with autologous transplantation (NCR National Cancer Registry 2006). In contrast only 30.8% (n=12) of participants undergoing allogeneic transplant were in the 50-69 age group, 38.5% (n=15) were in the 35-49 group, 17.9% (n=7) were in the 26-34 group and 12.8% (n=5) were in the 26-34 age group. This also reflects the normal age distribution of haematological malignancies that are potentially curable (table 6.1).

It was clear across both groups that more men than women were recruited to the study. In the group that underwent autologous transplant, 62.1% (n=18) were male and 37.9% (n=11) were female. For those who underwent allogeneic

transplant, 69.2% (n=27) were male and 30.8% (n=12) were female (Average ratio of 2:1) (table 6.1). The higher percentage of males receiving a transplant (autologous or allogeneic) for treatment of haematological malignancies reflects national trends (National Cancer Registry 2006).

The education level of the participants was recorded in order to determine if it was a contributing factor in the participants' response to 'Open Window'. There are no Irish data to suggest that those with a higher level of education have a greater appreciation or understanding of the arts but due to the novel nature of 'Open Window' and its context, it was decided to include it as a variable. In the autologous group, over half of participants attended secondary/senior school only (58.6% n=17), 24.2% (n=7) completed a certificate or diploma programme, 13.8% (n=4) were graduates and 3.4% (n=4) were post graduates. In the allogeneic group, 51.3% (n=20) attended secondary/senior school, 10.3% (n=4) completed a certificate or diploma programme, 28.2% (n=11) were graduates and 10.3% (n=4) were post graduates (table 6.1).

#### 6.4.2 Expectations Questionnaire

##### *6.4.2.1 Results from both groups*

Participants' expectations in relation to the experience of having a transplant were identified using the semi structured interviews when they were asked about how they expected to respond physically and psychologically to treatment and recovery. Both groups commented equally in terms of their physical and psychological expectations. Physical symptoms such as nausea, vomiting, diarrhoea, and fatigue were the main expectations with particular reference to concern about the side effects of medication. In relation to psychological expectations, many participants commented on the need for positive thinking in dealing with the treatment and recovery (Appendix 19b & 20).

The expectations questionnaire comprised a single question with a likert scale asking participants to rate their overall experience of having a stem cell or bone marrow transplant as being much better, a little better, as expected, a little worse, or much worse than expected. The second part of this questionnaire asked participants to list three things that they thought were positive about their experience and the third part asked participants to list three things that they perceived as negative.

The overall scores between the two groups showed that 59% (n=23) of those participants who underwent allogeneic transplant felt that the experience was better than expected (table 6.2). This is in contrast to only 37% (n=10) of those who underwent autologous transplant felt that the experience was better than expected. The differences between the groups continue with 33.3% (n=9) of the autologous group indicating that the experience of having a transplant was worse than expected whereas only 25.6% (n=10) of the allogeneic group felt this. Eight participants from the autologous group (29.6%) indicated that the experience was as they expected it to be whereas only 15.4% (n=6) of allogeneic group expressed this (table 6.6). Chi-square test for independence shows the difference between the groups is not statistically significant ( $p = .184$ ) (table 6.3).

Table 6.2 Expectations: differences between the groups

**Q1 - Please rate your experience of having a stem cell or bone marrow transplant by ticking the box appropriate to you \* AutoAllo Crosstabulation**

			AutoAllo		Total
			Auto	Allo	
Q1 - Please rate your experience of having a stem cell or bone marrow transplant by ticking the box appropriate to you	Worse	Count	9	10	19
		% within AutoAllo	33.3%	25.6%	28.8%
	As expected	Count	8	6	14
		% within AutoAllo	29.6%	15.4%	21.2%
	Better	Count	10	23	33
		% within AutoAllo	37.0%	59.0%	50.0%
Total	Count	27	39	66	
	% within AutoAllo	100.0%	100.0%	100.0%	

Table 6.3 Chi-Square Test

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	3.390 <sup>a</sup>	2	.184
Continuity Correction			
Likelihood Ratio	3.408	2	.182
Linear-by-Linear Association	1.857	1	.173
N of Valid Cases	66		

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 5.73.

Table 6.4 shows the factors that were identified by both groups as adding positively to their experience. Support structures in the form of family and friends were rated highest along with medical/nursing staff, information, TV/Internet/DVD, a positive mental attitude and information were ranked next in that order.

Table 6.4 Positive Factors for both Groups

**Q2 Please list 3 factors that added to your experience of having a stem cell transplant \***  
**AutoAllo**

	Auto		Allo		Total	
	Count	Column %	Count	Column %	Count	Column %
\$Q2 Family/Friends	14	66.7	12	48.0	26	56.5
Medical/Nursing Staff	11	52.4	13	52.0	24	52.2
Information	4	19.0	7	28.0	11	23.9
TV/Internet/DVDs	0	0.0	8	32.0	8	17.4
Positive Mental Attitude	2	9.5	5	20.0	7	15.2
Isolation was reassuring/safe	2	9.5	1	4.0	3	6.5
Apartment and the day unit	2	9.5	1	4.0	3	6.5
Open Window	1	4.8	1	4.0	2	4.3
Good recovery	0	0.0	2	8.0	2	4.3
Complications not bad	1	4.8	1	4.0	2	4.3
Prayer/faith	1	4.8	1	4.0	2	4.3
Ancillary Staff	1	4.8	0	0.0	1	2.2
Hygiene good	0	0.0	1	4.0	1	2.2
Total	21	100.0	25	100.0	46	100.0

The main factors identified by both groups that did not add to their experience of having a transplant were food, side effects of medication, isolation, confinement, communication difficulties, homesickness and uncertainty in that order. Some differences were seen in the autologous group with isolation being ranked first followed by food, confinement, side effects of medication, cold clinical environment, communication difficulties and loneliness (table 6.5).

Table 6.5 Negative Factors for both Groups

**Q3 Please list 3 factors that did not add to your experience of having a stem cell transplant \***  
**AutoAllo**

	Auto		Allo		Total	
	Count	Column %	Count	Column %	Count	Column %
\$Q3 Food	4	26.7	10	38.5	14	34.1
Isolation	5	33.3	8	30.8	13	31.7
Side effects of medication	3	20.0	10	38.5	13	31.7
Confinement	4	26.7	3	11.5	7	17.1
Communication difficulties	2	13.3	3	11.5	5	12.2
Cold clinical environment	2	13.3	1	3.8	3	7.3
Lonely	2	13.3	1	3.8	3	7.3
Homesick	0	0.0	3	11.5	3	7.3
Uncertainty	0	0.0	3	11.5	3	7.3
No mirror/poor shower	1	6.7	1	3.8	2	4.9
Too many different nurses	1	6.7	1	3.8	2	4.9
Insomnia	1	6.7	1	3.8	2	4.9
Too much negative information	0	0.0	2	7.7	2	4.9
Boredom	0	0.0	2	7.7	2	4.9
Complications of treatment	0	0.0	1	3.8	1	2.4
Leaving the unit was difficult	1	6.7	0	0.0	1	2.4
No view through the window	1	6.7	0	0.0	1	2.4
Total	15	100.0	26	100.0	41	100.0

#### 6.4.2.2 Expectations Questionnaire - Results from Autologous Group

As shown in table 6.1, a total of 29 participants were recruited to the autologous group, 14 of whom were randomly allocated to the intervention sample and 15 to

the control sample. In relation to gender, 71.4% (n=10) participants in the intervention sample of the autologous group were male and 28.6% (n=4) were female. Fifty-three percent (n=8) of those in the control sample were male and 46.7% (n=7) were female (table 6.6).

Table 6.6 Autologous Group: Gender of participants in the intervention and control samples

			Gender			
Allocation			Frequency	Percent	Valid Percent	Cumulative Percent
Intervention	Valid	Male	10	71.4	71.4	71.4
		Female	4	28.6	28.6	100.0
		Total	14	100.0	100.0	
Control	Valid	Male	8	53.3	53.3	53.3
		Female	7	46.7	46.7	100.0
		Total	15	100.0	100.0	

When the results between the intervention and control samples of the autologous group were examined, apparent differences emerged. The findings show that 61.5% (n=8) of the intervention group indicated that the experience of having a transplant was better than expected whereas only 14.3% (n=2) of the control group indicated this. Twenty-three percent (n=3) of the intervention group indicated that the experience was a little worse or much worse than expected whereas 42.9% (n=6) of the control group felt this (table 6.7). Chi-square test for independence shows the difference between the groups is not statistically significant ( $p = .496$ ). The value in the second row (Continuity Correction) is used in this instance as 2 cells have an expected count of less than 5 and this test compensates for the overestimation of the chi-square value when used with a 2 by 2 table. (table 6.8).

Table 6.7 Autologous Group: Differences in Expectations between intervention and control samples

**Q1 - Please rate your experience of having a stem cell or bone marrow transplant by ticking the box appropriate to you \* Allocation Crosstabulation**

			Allocation		Total
			Intervention	Control	
Q1 - Please rate your experience of having a stem cell or bone marrow transplant by ticking the box appropriate to you	Worse	Count	3	6	9
		% within Allocation	23.1%	42.9%	33.3%
	As expected	Count	2	6	8
		% within Allocation	15.4%	42.9%	29.6%
	Better	Count	8	2	10
		% within Allocation	61.5%	14.3%	37.0%
Total		Count	13	14	27
		% within Allocation	100.0%	100.0%	100.0%

Table 6.8 Chi-Square test for Autologous Group

**Chi-Square Tests**

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	1.187 <sup>b</sup>	1	.276		
Continuity Correction <sup>a</sup>	.464	1	.496		
Likelihood Ratio	1.205	1	.272		
Fisher's Exact Test				.420	.249
Linear-by-Linear Association	1.143	1	.285		
N of Valid Cases	27				

a. Computed only for a 2x2 table

b. 2 cells (50.0%) have expected count less than 5. The minimum expected count is 4.33.

When asked to list three things that added to their experience of having a transplant, both groups identified family/friends, medical/nursing staff and information as the top three factors. Interestingly the intervention group listed the reassurance of isolation and the facility of the apartment and day unit in joint 4<sup>th</sup> place as positive factors. In contrast the control group listed positive mental attitude and prayer/faith as important factors in joint 4<sup>th</sup> place (table 6.9).



Table 6.9 Autologous Group: Positive Factors

**Q2 Please list 3 factors that added to your experience of having a stem cell trasnplant \***  
**Allocation**

	Allocation				Total	
	Intervention		Control		Count	Column %
	Count	Column %	Count	Column %		
\$Q2 Family/Friends	6	50.0	8	88.9	14	66.7
Medical/Nursing Staff	8	66.7	3	33.3	11	52.4
Information	2	16.7	2	22.2	4	19.0
Positive Mental Attitude	1	8.3	1	11.1	2	9.5
Isolation was reassuring/safe	2	16.7	0	0.0	2	9.5
Apartment and the day unit	2	16.7	0	0.0	2	9.5
Open Window	1	8.3	0	0.0	1	4.8
Ancillary Staff	1	8.3	0	0.0	1	4.8
Complications not bad	1	8.3	0	0.0	1	4.8
Prayer/faith	0	0.0	1	11.1	1	4.8
Total	12	100.0	9	100.0	21	100.0

The third part of this questionnaire asked the participants to list 3 factors that they felt did not add to their experience of having a transplant. The participants in the intervention group listed isolation, food, and confinement as the top three factors whereas the control group listed confinement and side effects of medication as the top two factors with isolation, no mirror/shower, cold clinical environment, communication difficulties, loneliness and no view through the window as their joint third factors (table 6.10). It should be noted that as so few people provided comments in these sections, these are not reliable data.

Table 6.10 Autologous Group: Negative Factors

**Q3 Please list 3 factors that did not add to your experience of having a stem cell transplant \*  
Allocation**

	Allocation				Total	
	Intervention		Control		Count	Column %
	Count	Column %	Count	Column %		
\$Q3 Isolation	4	44.4	1	16.7	5	33.3
Food	4	44.4	0	0.0	4	26.7
Confinement	2	22.2	2	33.3	4	26.7
Side effects of medication	1	11.1	2	33.3	3	20.0
Cold clinical environment	1	11.1	1	16.7	2	13.3
Communication difficulties	1	11.1	1	16.7	2	13.3
Lonely	1	11.1	1	16.7	2	13.3
No mirror/poor shower	0	0.0	1	16.7	1	6.7
Too many different nurses	1	11.1	0	0.0	1	6.7
Leaving the unit was difficult	1	11.1	0	0.0	1	6.7
No view through the window	0	0.0	1	16.7	1	6.7
Insomnia	1	11.1	0	0.0	1	6.7
Total	9	100.0	6	100.0	15	100.0

There is a clear difference between the experience of males and females in the autologous group with only 5.6% (n=1) of males indicating that the experience was worse than expected compared with 88.9% (n=8) of females saying this. Fifty percent (n=9) of males felt that the experience was better than expected but only 11.1% (n=1) females indicated this. Forty-four percent (n=8) males indicated that the experience was as expected but no females felt this (table 6.11).

Table 6.11 Autologous Group: Differences in expectations according to Gender

Q1 - Please rate your experience of having a stem cell or bone marrow transplant by ticking the box appropriate to you \* Gender Crosstabulation

			Gender		Total
			Male	Female	
Q1 - Please rate your experience of having a stem cell or bone marrow transplant by ticking the box appropriate to you	Worse	Count	1	8	9
		% within Gender	5.6%	88.9%	33.3%
	As expected	Count	8	0	8
		% within Gender	44.4%	.0%	29.6%
	Better	Count	9	1	10
		% within Gender	50.0%	11.1%	37.0%
Total	Count	18	9	27	
	% within Gender	100.0%	100.0%	100.0%	

This is also evident with the qualitative data which show that men make 57.45% references (n=70) to their expectations of how they will respond to the treatment physically and females make 42.55% (n=42) (figure 6.2). Fourteen men (73.68%) and only 5 women (26.32%) referred to their psychological expectations (figure 6.3). Even allowing for there being twice as many men (n=45) in the study as females (n=23), it seems that men did verbalise their expectations. Not only did men refer to their physical and psychological expectations as much as women they also seemed to spend equal amounts of time discussing them. This is evident in how long they spent talking about the subject and this is represented in the number of words used (figure 6.4).

Figure 6.2: Physical Expectations by gender

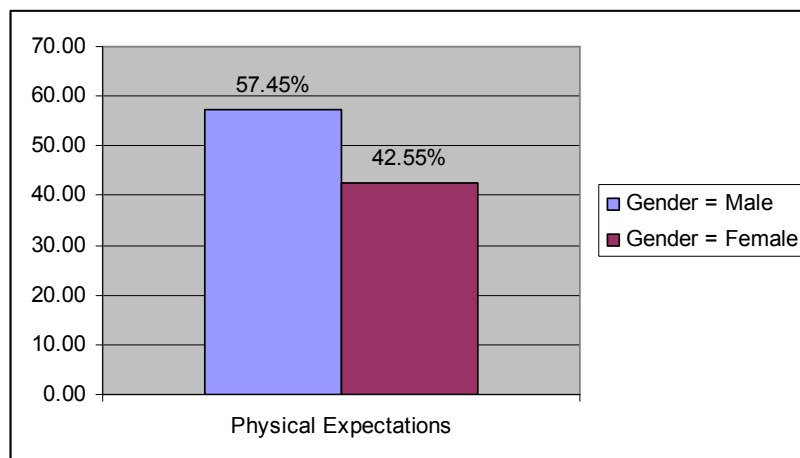


Figure 6.3: Psychological Expectations by gender

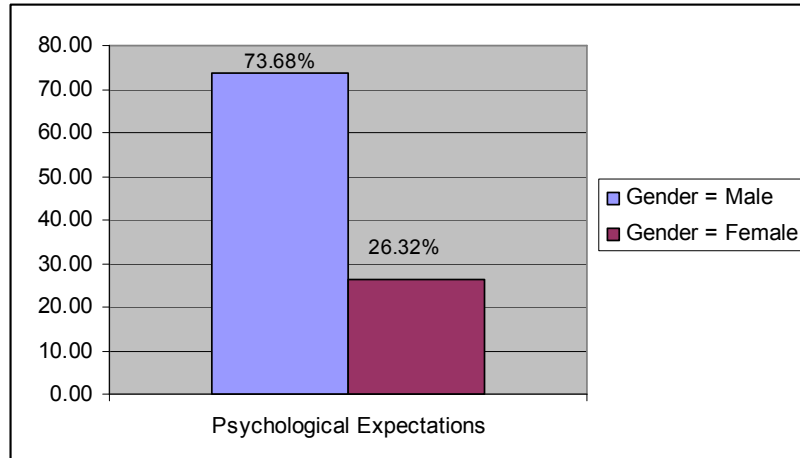
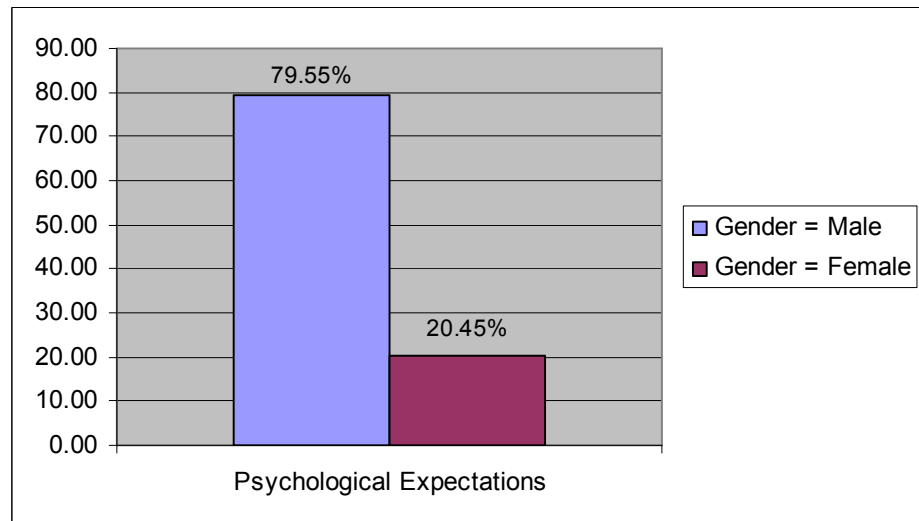


Figure 6.4 Percentage of word references for psychological expectations by gender



#### 6.4.2.3 Expectations Questionnaire - Results from Allogeneic Groups

Demographic data (table 6.2) shows that of the total of 39 participants recruited to the allogeneic group, 22 were randomly allocated to the intervention sample and 17 to the control sample.

Sixty-eight percent (n=15) of those in the intervention sample of the allogeneic group were male and almost 32% (n=7) were female. In the control sample, 70.6% (n=12) were male and 29.4% (n=5) were female (table 6.12).

Table 6.12 Allogeneic Group: Gender according to intervention and control samples

Allocation			Frequency	Percent	Valid Percent	Cumulative Percent
Intervention	Valid	Male	15	68.2	68.2	68.2
		Female	7	31.8	31.8	100.0
		Total	22	100.0	100.0	
Control	Valid	Male	12	70.6	70.6	70.6
		Female	5	29.4	29.4	100.0
		Total	17	100.0	100.0	

Similar to the autologous groups, when the differences between the intervention and control samples of the allogeneic groups were examined, differences were evident. The majority (68.2%, n=15) of the intervention group felt that the experience of having a transplant was better than expected whereas only 47% (n=8) of the control sample felt this. The difference between the groups is not so marked in relation to the experience being worse than expected with 28% (n=6) of the intervention group and 23.5% (n=4) of the control group indicating this. The difference in percentages arises from the control sample indicating that 29.4% (n=5) felt the experience was as expected and only 4.5% of the intervention group felt this (table 6.13). Chi-square test for independence shows the difference between the groups is not statistically significant ( $p = 1.000$ ). The value in the second row (Continuity Correction) is used in this instance as 2 cells

have an expected count of less than 5 and this test compensates for the overestimation of the chi-square value when used with a 2 by 2 table. (table 6.14).

Table 6.13 Allogeneic Group: Differences in expectations between the intervention and control samples

**Q1 - Please rate your experience of having a stem cell or bone marrow transplant by ticking the box appropriate to you \* Allocation Crosstabulation**

			Allocation		Total
			Intervention	Control	
Q1 - Please rate your experience of having a stem cell or bone marrow transplant by ticking the box appropriate to you	Worse	Count	6	4	10
		% within Allocation	27.3%	23.5%	25.6%
	As expected	Count	1	5	6
		% within Allocation	4.5%	29.4%	15.4%
	Better	Count	15	8	23
		% within Allocation	68.2%	47.1%	59.0%
Total		Count	22	17	39
		% within Allocation	100.0%	100.0%	100.0%

Table 6.14 Chi-Square Tests for differences in the Allogeneic Group

**Chi-Square Tests**

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	.070 <sup>b</sup>	1	.791		
Continuity Correction <sup>a</sup>	.000	1	1.000		
Likelihood Ratio	.071	1	.790		
Fisher's Exact Test				1.000	.544
Linear-by-Linear Association	.069	1	.793		
N of Valid Cases	39				

a. Computed only for a 2x2 table

b. 1 cells (25.0%) have expected count less than 5. The minimum expected count is 4.36.

When answering the second part of this questionnaire, participants in the intervention group listed Family/Friends (53.3%), Medical/Nursing Staff (46.7%) and Information (33.3%) as the top three factors that added to their experience of having a transplant. Those in the control group listed Medical/Nursing Staff (60%) followed by Family/Friends and TV/Internet/DVD's jointly at 40% as

their top three factors (table 6.15). Interestingly the intervention group listed TV/Internet/DVDs lower as fourth on their list at 26.7% (table 6.15).

Table 6.15 Allogeneic Group: Positive Factors

**Q2 Please list 3 factors that added to your experience of having a stem cell transplant \* Allocation**

		Allocation				Total	
		Intervention		Control		Count	Column %
		Count	Column %	Count	Column %		
\$Q2	Medical/Nursing Staff	7	46.7	6	60.0	13	52.0
	Family/Friends	8	53.3	4	40.0	12	48.0
	TV/Internet/DVDs Information	4	26.7	4	40.0	8	32.0
	Positive Mental Attitude	5	33.3	2	20.0	7	28.0
	Good recovery	2	13.3	3	30.0	5	20.0
	Open Window	1	6.7	1	10.0	2	8.0
	Isolation was reassuring/safe	1	6.7	0	0.0	1	4.0
	Complications not bad	1	6.7	0	0.0	1	4.0
	Prayer/faith	0	0.0	1	10.0	1	4.0
	Apartment and the day unit	1	6.7	0	0.0	1	4.0
	Hygiene good	0	0.0	1	10.0	1	4.0
	<b>Total</b>	<b>15</b>	<b>100.0</b>	<b>10</b>	<b>100.0</b>	<b>25</b>	<b>100.0</b>

Participants from the intervention group listed Side effects of medication (40%), Isolation (33.3%) and Food (26.7) as the top three factors that did not add to their experience of having a transplant. These same factors were listed as the top three for the control group also with food at 54.5%, side effects of medication at 36.4%, and isolation at 27.3% (table 6.16).

Table 6.16 Allogeneic Group: Negative Factors

Q3 Please list 3 factors that did not add to your experience of having a stem cell transplant \*  
Allocation

	Allocation				Total	
	Intervention		Control		Count	Column %
	Count	Column %	Count	Column %		
\$Q3 Food	4	26.7	6	54.5	10	38.5
Side effects of medication	6	40.0	4	36.4	10	38.5
Isolation	5	33.3	3	27.3	8	30.8
Confinement	2	13.3	1	9.1	3	11.5
Communication difficulties	3	20.0	0	0.0	3	11.5
Homesick	2	13.3	1	9.1	3	11.5
Uncertainty	3	20.0	0	0.0	3	11.5
Too much negative information	2	13.3	0	0.0	2	7.7
Boredom	1	6.7	1	9.1	2	7.7
No mirror/poor shower	0	0.0	1	9.1	1	3.8
Cold clinical environment	0	0.0	1	9.1	1	3.8
Complications of treatment	0	0.0	1	9.1	1	3.8
Too many different nurses	0	0.0	1	9.1	1	3.8
Lonely	1	6.7	0	0.0	1	3.8
Insomnia	0	0.0	1	9.1	1	3.8
Total	15	100.0	11	100.0	26	100.0

Gender differences in expectations are illustrated in table 6.19. This shows very little difference in terms of how they felt their experience matched their expectations. Fifty nine percent (n=16) of males and 58.3% of females (n=7) felt that the experience was better than expected; 29.5% (n=7) of males and 25% (n=3) of females indicated that the experience was worse than expected with only 14.8% (n=4) of males and 16.7% (n=3) of females feeling that it was as expected (table 6.17).



Table 6.17 Allogeneic Group: Differences in expectations according to Gender

**Q1 - Please rate your experience of having a stem cell or bone marrow transplant by ticking the box appropriate to you \* Gender Crosstabulation**

			Gender		Total
			Male	Female	
Q1 - Please rate your experience of having a stem cell or bone marrow transplant by ticking the box appropriate to you	Worse	Count	7	3	10
		% within Gender	25.9%	25.0%	25.6%
	As expected	Count	4	2	6
		% within Gender	14.8%	16.7%	15.4%
	Better	Count	16	7	23
		% within Gender	59.3%	58.3%	59.0%
Total	Count	27	12	39	
	% within Gender	100.0%	100.0%	100.0%	

When tested separately, it is clear that the difference between the intervention and control samples in the allogeneic and autologous groups is not statistically significant, however, when the intervention samples from both the autologous and allogeneic groups are tested together and likewise with the control samples, the difference between the groups is quite different with 65.7% (n=23) of those in the intervention sample indicating that they had a better experience than expected but only 32.3% (n=10) in the control sample reporting this (table 6.18). Chi-Square tests show that the difference between these samples is statistically significant ( $p < 0.05$ ) ( $p = .008$ ) (table 6.19). This indicates that those participants who experienced ‘Open Window’ were more likely to have a better experience than expected than those who did not.

Table 6.18 Difference between intervention and control samples across the groups

**Q1 - Please rate your experience of having a stem cell or bone marrow transplant by ticking the box appropriate to you \* Allocation Crosstabulation**

			Allocation		Total
			Intervention	Control	
Q1 - Please rate your experience of having a stem cell or bone marrow transplant by ticking the box appropriate to you	Worse	Count	9	10	19
		% within Allocation	25.7%	32.3%	28.8%
	As expected	Count	3	11	14
		% within Allocation	8.6%	35.5%	21.2%
	Better	Count	23	10	33
		% within Allocation	65.7%	32.3%	50.0%
Total	Count	35	31	66	
	% within Allocation	100.0%	100.0%	100.0%	

Table 6.19 Chi-Square test for the intervention and control samples

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	9.538 <sup>a</sup>	2	.008
Continuity Correction			
Likelihood Ratio	9.933	2	.007
Linear-by-Linear Association	3.487	1	.062
N of Valid Cases	66		

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 6.58.

When the same tests are conducted in relation to age and education level, there is no statistically significant difference between the groups; however, a statistically significant difference is evident ( $p < 0.05$ ) ( $p = .007$ ) between males and females (table 6.22). This indicates that females were more likely to have a worse experience than males. In this test, the first test applied was Pearson Chi-square. The approximation of the Chi-square distribution is only acceptable if no more than 20% of the events have expected frequencies below 5. For this reason some categories had to be collapsed before the test could be conducted (table 6.20 converted to table 6.21). Where there is a very small sample size the Fisher exact test was used instead of the Chi-square.

Table 6.20 Difference between males and females across the groups

**Q1 - Please rate your experience of having a stem cell or bone marrow transplant by ticking the box appropriate to you \* Gender Crosstabulation**

			Gender		Total
			Male	Female	
Q1 - Please rate your experience of having a stem cell or bone marrow transplant by ticking the box appropriate to you	Worse	Count	3	6	9
		% within Gender	12.0%	60.0%	25.7%
	As expected	Count	3	0	3
		% within Gender	12.0%	.0%	8.6%
	Better	Count	19	4	23
		% within Gender	76.0%	40.0%	65.7%
Total	Count	25	10	35	
	% within Gender	100.0%	100.0%	100.0%	

Table 6.21 Difference between males and females across the groups – converted table

**Q1 - Please rate your experience of having a stem cell or bone marrow transplant by ticking the box appropriate to you \* Gender Crosstabulation**

			Gender		Total
			Male	Female	
Q1 - Please rate your experience of having a stem cell or bone marrow transplant by ticking the box appropriate to you	Worse	Count	3	6	9
		% within Gender	12.0%	60.0%	25.7%
	Not worse	Count	22	4	26
		% within Gender	88.0%	40.0%	74.3%
Total	Count	25	10	35	
	% within Gender	100.0%	100.0%	100.0%	

Table 6.22 Chi-Square test for differences between males and females

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	8.615 <sup>b</sup>	1	.003		
Continuity Correction <sup>a</sup>	6.286	1	.012		
Likelihood Ratio	8.097	1	.004		
Fisher's Exact Test				.007	.007
Linear-by-Linear Association	8.369	1	.004		
N of Valid Cases	35				

a. Computed only for a 2x2 table

b. 1 cells (25.0%) have expected count less than 5. The minimum expected count is 2.57.

## 6.5 ‘Open Window’ Questionnaire

This section presents the findings from the ‘Open Window’ survey questionnaire which was administered to the 36 participants in the intervention groups (22 from the allogeneic group and 14 from the autologous group). This questionnaire comprised 30 questions which were divided into 4 sections. The first section contained a list of 11 statements that participants were asked to make a circle around the box that best represented their view. The first statement asked those in the intervention groups to indicate if they felt ‘Open Window’ helped them deal with being confined to their room. Eighty one percent (n=18) of those who underwent allogeneic transplant agreed or strongly agreed that it did and 50% (n=7) of those in the autologous group also agreed or strongly agreed with this statement. Three participants from the allogeneic group (13.6%) and 28.6% (n=4) of the autologous group disagreed or strongly disagreed with this statement (table 6.23).

Table 6.23 ‘Open Window’ helped me deal with being confined to my room

**Q1 'Open Window' helped me deal with being confined to my room. \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q1 'Open Window' helped me deal with being confined to my room.	Agree or Strongly Agree	Count	7	18	25
		% within Allo/Auto	50.0%	81.8%	69.4%
	Undecided	Count	3	1	4
		% within Allo/Auto	21.4%	4.5%	11.1%
	Disagree or Strongly Disagree	Count	4	3	7
		% within Allo/Auto	28.6%	13.6%	19.4%
Total	Count	14	22	36	
	% within Allo/Auto	100.0%	100.0%	100.0%	

The second statement asked participants from the intervention groups to indicate if they agreed or disagreed that ‘Open Window’ did not help them deal with the experience of having a transplant. The majority (63.6%, n=14) of those in the allogeneic group disagreed or strongly disagreed with this statement and only 21.4% (n=3) of the autologous group disagreed or strongly disagreed. Five

(35.7%) participants from the autologous group agreed or strongly agreed that ‘Open Window’ did not help them deal with the experience of having a transplant and 42.9% (n=6) of the autologous group were undecided about this. In contrast, only 22.7% (n=5) of the allogeneic group agreed or strongly agreed with this statement and 13.6% (n=3) were undecided (table 6.24).

Table 6.24 ‘Open Window’ did not help me deal with the experience of having a transplant

**Q2 'Open Window' did not help me deal with the experience of having a stem cell transplant. \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q2 'Open Window' did not help me deal with the experience of having a stem cell transplant.	Agree or Strongly Agree	Count	5	5	10
		% within Allo/Auto	35.7%	22.7%	27.8%
	Undecided	Count	6	3	9
		% within Allo/Auto	42.9%	13.6%	25.0%
	Disagree or Strongly Disagree	Count	3	14	17
		% within Allo/Auto	21.4%	63.6%	47.2%
Total	Count	14	22	36	
	% within Allo/Auto	100.0%	100.0%	100.0%	

The third statement asked participants if they agreed or disagreed that ‘Open Window’ gave them a sense of connection with the outside world. The majority (86.4%, n=19) of those in the allogeneic group agreed or strongly agreed with this statement and 13.6% (n=3) disagreed or strongly disagreed. A smaller percentage, 64.3% (n=9), of the autologous group agreed or strongly agreed with this statement and 21.3% (n=3) disagreed or strongly disagreed. None of the allogeneic group were undecided about this statement and 14.3% (n=2) of the autologous group were undecided (table 6.25).

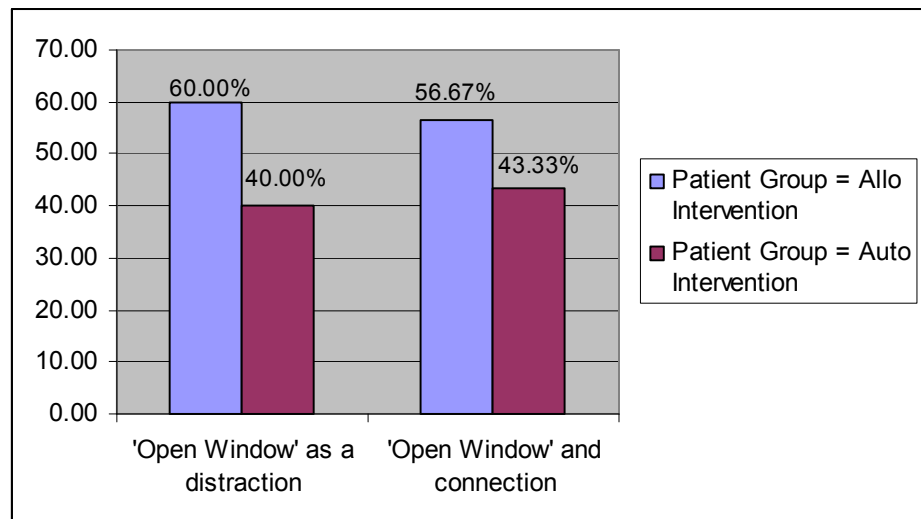
Table 6.25 'Open Window' gave me a sense of connection with the outside world

Q3 'Open Window' gave me a sense of connection with the outside world. \* Allo/Auto Crosstabulation

			Allo/Auto		Total
			Auto	Allo	
Q3 'Open Window' gave me a sense of connection with the outside world.	Agree or Strongly Agree	Count	9	19	28
		% within Allo/Auto	64.3%	86.4%	77.8%
	Undecided	Count	2	0	2
		% within Allo/Auto	14.3%	.0%	5.6%
	Disagree or Strongly Disagree	Count	3	3	6
		% within Allo/Auto	21.4%	13.6%	16.7%
Total		Count	14	22	36
		% within Allo/Auto	100.0%	100.0%	100.0%

Qualitative data indicates that both groups felt that the main value of 'Open Window' was its ability to distract them from their immediate environment and situation and the sense of connection it provided with familiar places and/or family outside the Denis Burkitt Unit (Appendix 22). Sixty-percent and 57% of those in the allogeneic intervention sample and 40% and 43% of the autologous intervention sample identified distraction (n=31) and connection (n=30) with 54 and 56 word references respectively (figure 6.5).

Figure 6.5 Value of 'Open Window'



Although participants did not use the term ‘connection’ directly it encompassed terms such as contentment, personal, home, relaxing and exciting. It seemed to have the effect of connecting participants with people and places outside their immediate environment.

- “ you’re locked into this place, but not locked I don’t mean locked ... you don’t have much of an option of going of around town and for someone that’s an outdoors person and likes wildernesses and wild places and places away from civilisation, ‘Open Window’ takes away this feeling of being trapped in a box or in a prison come cellar or whatever it is. The fact that you look at the wall and you can see horses racing out there with a forest in behind them and a car or whatever’s in behind that again, or lakes or boats or cows, even calves you know, it takes away the feeling of being caged.”

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- “It was just unbelievable to be able to turn on a screen; on the wall and see you know my wife, my new child, like I’ve seen my baby on a wall before I’ve actually seen her you know that kind of a way.”

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- “I used to go for walks there I’d think about the future and of getting out and doing that again. It is kind of a personal thing and it made me think positively like ‘I will get out of here you know and I will, I will be able to do that again”

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Participants generally used the term ‘distraction’ directly and also described it as enjoying and interesting.

- “I found Open Windows very interesting and it kind of distracted myself from my illness and it gave me something to think about

and to enjoy, you know I did enjoy the Open Windows when I put it on, I really did and especially the animals.”

Documents\Auto Intervention Group C\T4\Au013IntT4

The fourth statement asked participants if they agreed or disagreed that ‘Open Window’ was boring. All (100%, n=22) of the allogeneic group disagreed or strongly disagreed that ‘Open Window’ was boring. In contrast, 71.4% (n=10) of the autologous group disagreed or strongly disagreed with 21.4% agreeing or strongly agreeing that it was boring (table 6.26).

Table 6.26 ‘Open Window’ was boring

**Q4 'Open Window' was boring. \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q4 'Open Window' was boring.	Agree or Strongly Agree	Count	3	0	3
		% within Allo/Auto	21.4%	.0%	8.3%
	Undecided	Count	1	0	1
		% within Allo/Auto	7.1%	.0%	2.8%
	Disagree or Strongly Disagree	Count	10	22	32
		% within Allo/Auto	71.4%	100.0%	88.9%
Total	Count	14	22	36	
	% within Allo/Auto	100.0%	100.0%	100.0%	

The fifth statement asked participants if they agreed or disagreed that ‘Open Window’ provided a soothing environment. A high percentage in both groups seemed to think that ‘Open Window’ did provide a soothing environment with 86.4% (n=19) of the allogeneic group and 71.4% of the autologous group agreeing or strongly agreeing and only 4.5% (n=1) of the allogeneic group and 21.4% (n=3) of the autologous group disagreeing or strongly disagreeing (table 6.27).



Table 6.27 ‘Open Window’ provided a soothing environment

**Q5 'Open Window' provided a soothing environment. \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q5 'Open Window' provided a soothing environment.	Agree or Strongly Agree	Count	10	19	29
		% within Allo/Auto	71.4%	86.4%	80.6%
	Undecided	Count	1	2	3
		% within Allo/Auto	7.1%	9.1%	8.3%
	Disagree or Strongly Disagree	Count	3	1	4
		% within Allo/Auto	21.4%	4.5%	11.1%
Total		Count	14	22	36
		% within Allo/Auto	100.0%	100.0%	100.0%

The results from statement 6 are very similar to question 5 with a high percentage of participants from both groups agreeing or strongly agreeing that ‘Open Window’ was relaxing (90.9% (n=20) of those in the allogeneic group and 78.6% (n=11) of the autologous group) (table 6.28).

Table 6.28 ‘Open Window’ was relaxing

**Q6 'Open Window' was relaxing. \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q6 'Open Window' was relaxing.	Agree or Strongly Agree	Count	11	20	31
		% within Allo/Auto	78.6%	90.9%	86.1%
	Undecided	Count	1	1	2
		% within Allo/Auto	7.1%	4.5%	5.6%
	Disagree or Strongly Disagree	Count	2	1	3
		% within Allo/Auto	14.3%	4.5%	8.3%
Total		Count	14	22	36
		% within Allo/Auto	100.0%	100.0%	100.0%

Qualitative data supports the findings from tables 6.25 and 6.26 with participants commenting on how it helped them relax and is reflected included in the percentages of those who valued the ability of ‘Open Window’ to distract and connect participants with the outside world.

- “What I would think of it [Open Window] is that it’s very relaxing, I would find it relaxing in that you could lie back and watch it and do a bit of thinking to yourself or whatever... or talk to yourself if you want”

Documents\Allo Intervention Group A\T4\A1022IntT4

- “They [the images] were relaxing when I watched them, you know you just lie there and you’re just in a trance... you’re not here, you’re in another world. That video with the cows grazing, I mean being born and reared in the country I felt I was in that field”

Documents\Auto Intervention Group C\T4\Au031IntT4

The percentage of participants from both groups who agreed or strongly agreed with the 7<sup>th</sup> statement that ‘Open Window’ provided gentle stimulation was somewhat lower in terms of a positive response than for other statements with 54.4% (n=12) in the allogeneic group and 50% (n=7) in the autologous group indicating this (table 6.29).

Table 6.29 ‘Open Window’ provided gentle stimulation

**Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q7 'Open Window' provided gentle stimulation.	Agree or Strongly Agree	Count	7	12	52.8%
		% within Allo/Auto	50.0%	54.5%	
	Undecided	Count	3	7	27.8%
		% within Allo/Auto	21.4%	31.8%	
	Disagree or Strongly Disagree	Count	4	3	19.4%
		% within Allo/Auto	28.6%	13.6%	
Total	Count	14	22	100.0%	
	% within Allo/Auto	100.0%	100.0%	100.0%	

The 8<sup>th</sup> statement asked participants to indicate whether they agreed or disagreed that seeing familiar places on ‘Open Window’ made them feel lonely. The majority (76.5%, n=13) of those in the allogeneic group indicated that they

disagreed or strongly disagreed with this statement with 23.5% (n=4) agreeing or strongly agreeing. The majority (77.8%, n=7) of the autologous group also disagreed or strongly disagreed with this statement with 22.2% (n=2) agreeing or strongly agreeing (table 6.30). Five participants from the autologous group and 5 from the allogeneic gave no response to this statement.

Table 6.30 ‘Open Window made me feel lonely when I saw familiar places

**Q8 'Open Window' made me feel lonely when I saw familiar places. \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q8 'Open Window' made me feel lonely when I saw familiar places.	Agree or Strongly Agree	Count	2	4	6
		% within Allo/Auto	22.2%	23.5%	23.1%
	Disagree or Strongly Disagree	Count	7	13	20
		% within Allo/Auto	77.8%	76.5%	76.9%
Total		Count	9	17	26
		% within Allo/Auto	100.0%	100.0%	100.0%

Participant responses from both groups for statement 9 were similar to statement 8. The majority (77.8%, n=7) of those in the allogeneic group and 66.7% (n=2) of the autologous group disagreed or strongly disagreed that ‘Open Window’ made them feel lonely when they saw images of their family. Only 22.2% (n=2) of the allogeneic group and 33.3% (n=1) of the autologous agreed or strongly agreed that it did (table 6.31). Eleven participants from the autologous group and 13 from the allogeneic group did not respond to this statement. Qualitative data provides some explanation of why some people found it lonely.

- “I found it very, very lonely because my husband took some pictures of the house and around the back and then there were a couple of photos of the grandchildren ... no I prefer not to look at those, I sort of prefer to close off a certain part of myself while I’m here”

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Table 6.31 'Open Window' made me feel lonely when I saw family images

**Q9 'Open Window' made me feel lonely when I saw family images. \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q9 'Open Window' made me feel lonely when I saw family images.	Agree or Strongly Agree	Count	1	2	25.0%
		% within Allo/Auto	33.3%	22.2%	
	Disagree or Strongly Disagree	Count	2	7	75.0%
		% within Allo/Auto	66.7%	77.8%	
Total		Count	3	9	100.0%
		% within Allo/Auto	100.0%	100.0%	

There were significant differences in the responses from each group for statement 10. Nineteen people (86.4%) from the allogeneic group agreed or strongly agreed that 'Open Window' helped to reduce the boredom and 9.1% (n=2) disagreed or strongly disagreed. In contrast, only 35.7% (n=5) of those in the autologous group agreed or strongly agreed that 'Open Window' helped to reduce the boredom and 50% (n=7) disagreed or strongly disagreed with 14.3% (n=2) being undecided (table 6.32).

Table 6.32 'Open Window' helped to reduce the boredom

**Q10 'Open Window' helped to reduce the boredom. \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q10 'Open Window' helped to reduce the boredom.	Agree or Strongly Agree	Count	5	19	24
		% within Allo/Auto	35.7%	86.4%	
	Undecided	Count	2	1	3
		% within Allo/Auto	14.3%	4.5%	
	Disagree or Strongly Disagree	Count	7	2	9
		% within Allo/Auto	50.0%	9.1%	
Total		Count	14	22	36
		% within Allo/Auto	100.0%	100.0%	

The last statement in this section asked the participants to indicate if they agreed or disagreed that the images on 'Open Window' were enjoyable. In the allogeneic group, 95.5% (n=21) agreed or strongly agreed that they were and

only 4.5% (n=1) disagreed or strongly disagreed. Similarly, 92.9% (n=13) of those in the autologous group agreed or strongly agreed with the statement and 7.1% (n=1) disagreed or strongly disagreed (table 6.33).

Table 6.33 'Open Window' images were enjoyable

**Q11 The 'Open Window' images were enjoyable. \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q11 The 'Open Window' images were enjoyable.	Agree or Strongly Agree	Count	13	21	34
		% within Allo/Auto	92.9%	95.5%	94.4%
	Disagree or Strongly Disagree	Count	1	1	2
		% within Allo/Auto	7.1%	4.5%	5.6%
Total		Count	14	22	36
		% within Allo/Auto	100.0%	100.0%	100.0%

Section 2 of the 'Open Window' questionnaire contained 8 statements with which participants were asked to indicate if they agreed or disagreed. The purpose of these statements was to determine which types of images were most popular. In the first statement participants were asked if they agreed or disagreed that they preferred to look at still images. Fifty percent (n=11) of those in the allogeneic group agreed or strongly agreed that they preferred the still images and a slightly lower percentage of 45.5% (n=10) disagreed or strongly disagreed with this statement with 4.5% (n=1) being undecided. A much lower percentage of 14.3% (n=2) in the autologous group agreed or strongly agreed with this statement with 71.4% disagreeing or strongly disagreeing (table 6.34).

Table 6.34 Preferred still images

**Q12 I preferred looking at the still images. \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q12 I preferred looking at the still images.	Agree or Strongly Agree	Count	2	11	13
		% within Allo/Auto	14.3%	50.0%	36.1%
	Undecided	Count	2	1	3
		% within Allo/Auto	14.3%	4.5%	8.3%
	Disagree or Strongly Disagree	Count	10	10	20
		% within Allo/Auto	71.4%	45.5%	55.6%
Total		Count	14	22	36
		% within Allo/Auto	100.0%	100.0%	100.0%

There was a much higher percentage of agreement between the groups in relation to statement 13. Almost ninety-one percent (n=20) of those in the allogeneic group agreed or strongly agreed that they preferred looking at the moving images with only 4.5% (n=1) disagreeing or strongly disagreeing. Slightly fewer (85.7%, n=12) of those in the autologous group agreed or strongly agreed with the statement, with 14.3% (n=2) disagreeing (table 6.35).

Table 6.35 Preferred moving images

**Q13 I preferred looking at the moving images. \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q13 I preferred looking at the moving images.	Agree or Strongly Agree	Count	12	20	32
		% within Allo/Auto	85.7%	90.9%	88.9%
	Undecided	Count	0	1	1
		% within Allo/Auto	.0%	4.5%	2.8%
	Disagree or Strongly Disagree	Count	2	1	3
		% within Allo/Auto	14.3%	4.5%	8.3%
Total	Count	14	22	36	
	% within Allo/Auto	100.0%	100.0%	100.0%	

There was almost unanimous agreement across the groups in response to statement 14. Ninety-four percent (n=16) of those in the allogeneic group and 100% (n=8) of the autologous group agreed or strongly agreed that they preferred looking at images of familiar places. Only 5.9% (n=1) of the allogeneic group disagreed with the statement (table 6.36). Six participants from the autologous group and 5 from the allogeneic group did not respond to this statement.

Table 6.36 Preferred images of familiar places

**Q14 I preferred looking at images of familiar places. \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q14 I preferred looking at images of familiar places.	Agree or Strongly Agree	Count	8	16	24
		% within Allo/Auto	100.0%	94.1%	96.0%
	Disagree or Strongly Disagree	Count	0	1	1
		% within Allo/Auto	.0%	5.9%	4.0%
Total		Count	8	17	25
		% within Allo/Auto	100.0%	100.0%	100.0%

A similar result was seen with statement 15 with 90.9% (n=10) of those in the allogeneic group agreeing or strongly agreeing that that they preferred looking at images of family. Both participants from the autologous group that responded to this statement agreed or strongly agreed with this statement. The reduced numbers responding to this statement may have been that some participants, particularly in the autologous group, chose not to have family images on ‘Open Window’. The main reason given for this was that they would not be in hospital that long or their family could visit as they were over the age of 14 (table 6.37). Twelve participants from the autologous group and 12 from the allogeneic group did not respond to this statement.

Table 6.37 Preferred images of family

**Q15 I preferred looking at images of family. \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q15 I preferred looking at images of family.	Agree or Strongly Agree	Count	2	10	12
		% within Allo/Auto	100.0%	90.9%	92.3%
	Disagree or Strongly Disagree	Count	0	1	1
		% within Allo/Auto	.0%	9.1%	7.7%
Total		Count	2	11	13
		% within Allo/Auto	100.0%	100.0%	100.0%

In response to statement 16, 72.7% (n=16) of those in the allogeneic group agreed or strongly agreed that the music accompanying the moving images was soothing and 9.1% (n=2) disagreed or strongly disagreed with 18.2% (n=4) undecided. In the autologous group 42.9% agreed or strongly agreed with this

statement and 21.4% (n=3) disagreed or strongly disagreed with 35.7% (n=5) being undecided (table 6.38).

Table 6.38 The music was soothing

**Q16 The music that accompanied the moving images was soothing. \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q16 The music that accompanied the moving images was soothing.	Agree or Strongly Agree	Count	6	16	22
		% within Allo/Auto	42.9%	72.7%	61.1%
	Undecided	Count	5	4	9
		% within Allo/Auto	35.7%	18.2%	25.0%
	Disagree or Strongly Disagree	Count	3	2	5
		% within Allo/Auto	21.4%	9.1%	13.9%
Total	Count	14	22	36	
	% within Allo/Auto	100.0%	100.0%	100.0%	

In relation to statement 17, there were marked differences in the responses from the groups. Sixteen (72.7%) of those in the allogeneic group agreed or strongly agreed with the statement that the music with the moving images was relaxing whereas only 42.9% of those in the autologous group felt this. Nine percent (n=2) of the allogeneic group disagreed or strongly disagreed with the statement and 21.4% (n=3) of the autologous group disagreed. Many were undecided with 18.2% (n=4) from the allogeneic group and 35.7% (n=5) from the autologous group indicating this (table 6.39).

Table 6.39 Music was relaxing

**Q17 The music that accompanied the moving images was relaxing. \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q17 The music that accompanied the moving images was relaxing.	Agree or Strongly Agree	Count	6	16	22
		% within Allo/Auto	42.9%	72.7%	61.1%
	Undecided	Count	5	4	9
		% within Allo/Auto	35.7%	18.2%	25.0%
	Disagree or Strongly Disagree	Count	3	2	5
		% within Allo/Auto	21.4%	9.1%	13.9%
Total	Count	14	22	36	
	% within Allo/Auto	100.0%	100.0%	100.0%	



Statement 18 asked participants to indicate if they agreed or disagreed that they did not like any of the images. Only 1 person (4.5%), from the allogeneic group, agreed with this statement (table 6.40).

Table 6.40 Did not like any of the images

**Q18 I did not like any of the images. \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q18 I did not like any of the images.	Agree or Strongly Agree	Count	0	1	1
		% within Allo/Auto	.0%	4.5%	2.8%
	Disagree or Strongly Disagree	Count	14	21	35
		% within Allo/Auto	100.0%	95.5%	97.2%
Total		Count	14	22	36
		% within Allo/Auto	100.0%	100.0%	100.0%

Participant responses to these statements suggest that ‘Open Window’ content was broad enough for most to find something that interested them. Qualitative data supports this view and when asked about their overall views or opinion of ‘Open Window’, the participants were happy to indicate what they liked or disliked about the images and provide a rationale for their opinion (Appendix 19c). This sub theme is titled ‘Appreciation of Art’ even though participants may not have been conscious they were engaging in this.

- “You need movement, to me that would crack me up like that smoking tree it looked like a tree on fire, it didn’t do anything for me whatsoever, being honest with you it didn’t make sense to me one bit”!

Documents\Allo Intervention Group A\T4\A1038\ntT4

- “The music, I would put it on mute but what I did like were the natural sounds I mean the one with the horse where you got that little bit of thunder in the background and the bird sounds yeah that was good, ok it was a bit too short ... but its not that I actually watched it, it’s kind of there in the background. I found I didn’t like the music on as much because it was kind of like elevator music”

Documents\Allo Intervention Group A\T4\AL042\ntT4

• Yeah the flower [image of wilting wild flower] one was totally alien. You see I don't care how good somebody is, or how intelligent somebody is, let them be artists or let them be doctors or nurses or whatever they want to be ... its very hard no matter how you're trained to study form of one thing or another, its very hard to look at an image on a wall and say well that's how it is! That's how it is if you feel well, but it's not how it is if you're lying on the edge of eternity!

Documents\Auto Intervention Group C\T4\Au015 Int T4

• All the pictures my sister took were bright and happy and cheerful. I liked that

Documents\Allo Intervention Group A\T7\AL026 T7

• "I liked looking at the river, it's lovely to look at with the sun you know coming around the corner and the reflections and that kind of stuff"

Documents\Allo Intervention Group A\T4\AI014IntT4

The last statement in this section asked participants to indicate if they agreed or disagreed that they preferred looking at television rather than 'Open Window'. Almost 32% (n=7) of the allogeneic group and 29% (n=4) of the autologous group agreed or strongly agreed that they did prefer looking at television whereas 50% (n=11) of both the allogeneic group and autologous group (n=7) disagreed or strongly disagreed with this statement. Eighteen percent (n=4) of the allogeneic group and 21.4% (n=3) of the autologous group were undecided about this statement (table 6.41).

Table 6.41 Preferred TV

**Q19 I preferred looking at TV. \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q19 I preferred looking at TV.	Agree or Strongly Agree	Count	4	7	11
		% within Allo/Auto	28.6%	31.8%	30.6%
	Undecided	Count	3	4	7
		% within Allo/Auto	21.4%	18.2%	19.4%
	Disagree or Strongly Disagree	Count	7	11	18
		% within Allo/Auto	50.0%	50.0%	50.0%
Total	Count	14	22	36	
	% within Allo/Auto	100.0%	100.0%	100.0%	

The third section of this questionnaire contains 5 questions that assess how participants used ‘Open Window’. The first question asks participants to indicate ‘yes’ or ‘no’ as to whether they were able to use the ‘Open Window’ technology. All participants in both groups indicated ‘Yes’ (table 6.42).

Table 6.42 Able to use the ‘Open Window’ technology

**Q20 I was able to use the 'Open Window' technology \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q20 I was able to use the 'Open Window' technology	Yes	Count	14	22	36
		% within Allo/Auto	100.0%	100.0%	100.0%
Total		Count	14	22	36
		% within Allo/Auto	100.0%	100.0%	100.0%

The second question asked participants to indicate the time of day they preferred to look at ‘Open Window’. The three options chosen most often by the participants from both groups were afternoon, evening time or there was no set pattern to when they looked at it. Just over half (59.1%, n=13) of the allogeneic group and 42.9% (n=6) of the autologous group chose ‘no set pattern’. Almost 14% (n=3) of the allogeneic group and 42.9% (n=6) of the autologous group chose evening and 18.2% (n=4) of the allogeneic and 7.1% (n=1) of the autologous group choosing afternoon. Only 2 participants (9.1%) from the allogeneic group preferred to look at it before going to sleep and 1 (7.1%) from

the autologous group 9.1% (n=2) indicated that they preferred it in the morning (table 6.43)

Table 6.43 Preferred time for looking at ‘Open Window’

**Q21 I preferred looking at 'Open Window' in the... \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q21 I preferred looking at 'Open Window' in the...	Morning (8am - 12md)	Count	1	0	1
		% within Allo/Auto	7.1%	.0%	2.8%
	Afternoon (12md - 5pm)	Count	1	4	5
		% within Allo/Auto	7.1%	18.2%	13.9%
	Evening (5.01pm – 10pm)	Count	6	3	9
		% within Allo/Auto	42.9%	13.6%	25.0%
	Before going to sleep	Count	0	2	2
		% within Allo/Auto	.0%	9.1%	5.6%
	There was no set pattern	Count	6	13	19
		% within Allo/Auto	42.9%	59.1%	52.8%
Total	Count	14	22	36	
	% within Allo/Auto	100.0%	100.0%	100.0%	

The pattern of how long the participants looked at ‘Open Window’ at any one time varied but both groups seemed to look at it mostly for ½ -1 hour with 61.9% (n=13) of the allogeneic group and 50% (n=7) of the autologous group choosing this option, and 7.1% (n=1) of the autologous group and 19.0% (n=4) of the allogeneic looking at for 1-2 hours. Two participants (9.5%, n=2) from the allogeneic group and 4 (28.6%) from the autologous group looked at it for less than 30 minutes and 4.8% (n=1) and 14.3% (n=2) respectively said the length of time they looked at it varied (table 6.44). One participant from the allogeneic group did not respond to this item.

Table 6.44 Length of time spent looking at ‘Open Window’

**Q22 On the days I looked at 'Open Window' I looked at it for... \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q22 On the days I looked at 'Open Window' I looked at it for...	Less than 30 minutes	Count	4	2	6
		% within Allo/Auto	28.6%	9.5%	17.1%
	½ hr – 1hr	Count	7	13	20
		% within Allo/Auto	50.0%	61.9%	57.1%
	More than 1 hour, up to 2 hours	Count	1	4	5
		% within Allo/Auto	7.1%	19.0%	14.3%
	More than 2 hours	Count	0	1	1
		% within Allo/Auto	.0%	4.8%	2.9%
	It Varied	Count	2	1	3
		% within Allo/Auto	14.3%	4.8%	8.6%
Total		Count	14	21	35
		% within Allo/Auto	100.0%	100.0%	100.0%

When asked how often they looked at ‘Open Window’ during the week, the majority said they looked at it 3-4 days/week, with 57.1% of the allogeneic group and 50% (n=7) of the autologous group choosing this option. Two participants (9.5%) from the allogeneic group and 5 (35.7%) from the autologous group said they looked at it 1-2 days/week. None of the autologous group and only 19% (n=4) of the allogeneic group watched it 5-6 days/week. An equal percentage of 14.3% (n=2) from the autologous group and 14.3% (n=2) from the allogeneic group watched it every day (table 6.45). One participant from the allogeneic did not respond to this item.

Table 6.45 How often participants viewed ‘Open Window’ during the week

**Q23 I looked at 'Open Window'... \* Allo/Auto Crosstabulation**

			Allo/Auto		Total	
			Auto	Allo		
Q23 I looked at 'Open Window'...	Every day	Count	2	3	5	
		% within Allo/Auto	14.3%	14.3%	14.3%	
	5-6 days/week	Count	0	4	4	
		% within Allo/Auto	.0%	19.0%	11.4%	
	3-4 days/week	Count	7	12	19	
		% within Allo/Auto	50.0%	57.1%	54.3%	
	1-2 days/week	Count	5	2	7	
		% within Allo/Auto	35.7%	9.5%	20.0%	
	Total		Count	14	21	35
			% within Allo/Auto	100.0%	100.0%	100.0%

When asked how often during the day they looked at ‘Open Window’ the majority of the participants in both groups indicated that it was once a day with 66.7% (n=14) of the allogeneic group and 85.7% (n=12) of the autologous group choosing this option. Nineteen percent (n=4) of the allogeneic and 14.3% (n=2) of the autologous group looked at it twice a day. Three participants (14.3%) from the allogeneic group said they looked at it intermittently throughout the day (table 6.46). One participant from the allogeneic group did not respond to this item.

Table 6.46 How many times ‘Open Window’ viewed on a daily basis

**Q24 On the days I looked at 'Open the Window' I looked at it... \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q24 On the days I looked at 'Open the Window' I looked at it...	Once a day	Count	12	14	26
		% within Allo/Auto	85.7%	66.7%	74.3%
	Twice a day	Count	2	4	6
		% within Allo/Auto	14.3%	19.0%	17.1%
	Intermittently throughout the day	Count	0	3	3
		% within Allo/Auto	.0%	14.3%	8.6%
Total	Count	14	21	35	
	% within Allo/Auto	100.0%	100.0%	100.0%	

The last section of this questionnaire contained 6 questions, the purpose of which was to assess which types of images were looked at most often. Almost 32% of the allogeneic group and 57.1% (n=8) of the autologous group said they looked at the still images 1-2 days/week. Similarly 35.7% (n=5) of the autologous group and 54.5% (n=12) of the allogeneic group looked at the still images 3-4 days/week. Only 7.1% (n=1) of the autologous group and 13.6% (n=3) of the allogeneic group looked at the still images every day (table 6.47).

Table 6.47 How often still images were viewed

**Q25 Still images \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q25 Still images	Always (Every day)	Count	1	3	4
		% within Allo/Auto	7.1%	13.6%	11.1%
	Sometimes (3-4 days/wk)	Count	5	12	17
		% within Allo/Auto	35.7%	54.5%	47.2%
	Seldom (1-2 days/wk)	Count	8	7	15
		% within Allo/Auto	57.1%	31.8%	41.7%
Total	Count	14	22	36	
	% within Allo/Auto	100.0%	100.0%	100.0%	

The second question in this section asked how often during the week the participants looked at the moving images. There seemed to be a slight increase in how often these were looked at. Only 13.6% (n=3) of the allogeneic and 42.9% (n=6) of the autologous group looked at the moving images 1-2 days/week. In contrast, 59.1% of the allogeneic group and 35.7% of the autologous group looked at these images 3-4 days/week with only 18.2% (n=4) of the allogeneic group and 7.1% (n=1) of the autologous group looking at the moving images 5-6 days/week. Very few participants (9.1% of the allogeneic group and 14.3% of the autologous group) looked at these images every day (table 6.48).

Table 6.48 How often moving images viewed

**Q26 Moving images \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q26 Moving images	Always (Every day)	Count	2	2	4
		% within Allo/Auto	14.3%	9.1%	11.1%
	Often (5-6 days/wk)	Count	1	4	5
		% within Allo/Auto	7.1%	18.2%	13.9%
	Sometimes (3-4 days/wk)	Count	5	13	18
		% within Allo/Auto	35.7%	59.1%	50.0%
Seldom (1-2 days/wk)	Count	6	3	9	
	% within Allo/Auto	42.9%	13.6%	25.0%	
Total	Count	14	22	36	
	% within Allo/Auto	100.0%	100.0%	100.0%	

When asked how often during the week they looked at the images of familiar places on ‘Open Window’, 15.8% (n=3) of the allogeneic group and 50% (n=4) of the autologous group said they looked at these images 1-2 days/week. Twenty-five percent (n=2) of the autologous group and 47.4% (n=9) of the allogeneic group looked at them 3-4 days/week. Almost 32% (n=6) of the allogeneic group and 12.5% (n=1) of the autologous group looked at images of familiar places 5-6 days/week with only 1 participant from each group (5.3% and 12.5% respectively) looking at these images every day (table 6.49). Six participants from the autologous group and 3 from the allogeneic group did not respond to this item.

Table 6.49 How often images of familiar places viewed

**Q27 Familiar places \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q27 Familiar places	Always (Every day)	Count	1	1	2
		% within Allo/Auto	12.5%	5.3%	7.4%
	Often (5-6 days/wk)	Count	1	6	7
		% within Allo/Auto	12.5%	31.6%	25.9%
	Sometimes (3-4 days/wk)	Count	2	9	11
		% within Allo/Auto	25.0%	47.4%	40.7%
	Seldom (1-2 days/wk)	Count	4	3	7
		% within Allo/Auto	50.0%	15.8%	25.9%
Total	Count	8	19	27	
	% within Allo/Auto	100.0%	100.0%	100.0%	

When asked about how frequently they looked at family images during the week, 1 participant (8.3%) from the allogeneic group and 1 participant (50%) from the autologous group looked at these images 1-2 days/week. In contrast, 50% (n=6) of the allogeneic group but only 1 (50%) of the autologous group looked at these images 3-4 days/week. In relation to looking at the family images either every day or 5-6 days/week, 8.3% (n=1) and 33.3% (n=4) of the allogeneic group respectively and none of the autologous group did this (table 6.50). Twelve



participants from the autologous group and 10 from the allogeneic group did not respond to this item.

Table 6.50 How often family images viewed

**Q28 Family images \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q28 Family images	Always (Every day)	Count	0	1	1
		% within Allo/Auto	.0%	8.3%	7.1%
	Often (5-6 days/wk)	Count	0	4	4
		% within Allo/Auto	.0%	33.3%	28.6%
	Sometimes (3-4 days/wk)	Count	1	6	7
		% within Allo/Auto	50.0%	50.0%	50.0%
	Seldom (1-2 days/wk)	Count	1	1	2
		% within Allo/Auto	50.0%	8.3%	14.3%
Total	Count	2	12	14	
	% within Allo/Auto	100.0%	100.0%	100.0%	

When asked how often during the week they listened to the music on 'Open Window' 9.5% (n=2) of the allogeneic group and 14.3% (n=2) of the autologous group said they listened to it every day. Only one participant (4.8%) from the allogeneic group and none of the autologous group listened to the music 5-6 days/week. A larger percentage listened to the music 3-4 days/week with 66.7% (n=14) of the allogeneic group and 28.6% (n=4) from the autologous group choosing this option. Fourteen percent (n=3) of the allogeneic group and 43% (n=6) of the autologous group listened to the music only 1-2 days/week and 14.3% (n=2) of the autologous group and 4.8% (n=1) of the allogeneic group never listened to it (table 6.51). One participant from the allogeneic group did not respond to this item.

Table 6.51 How often music was listened to

**Q29 Music \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q29 Music	Always (Every day)	Count	2	2	4
		% within Allo/Auto	14.3%	9.5%	11.4%
	Often (5-6 days/wk)	Count	0	1	1
		% within Allo/Auto	.0%	4.8%	2.9%
	Sometimes (3-4 days/wk)	Count	4	14	18
		% within Allo/Auto	28.6%	66.7%	51.4%
	Seldom (1-2 days/wk)	Count	6	3	9
		% within Allo/Auto	42.9%	14.3%	25.7%
	Never	Count	2	1	3
		% within Allo/Auto	14.3%	4.8%	8.6%
Total	Count	14	21	35	
	% within Allo/Auto	100.0%	100.0%	100.0%	

Thirty-six percent (n=8) of the allogeneic group and none of the autologous group watched television every day, however, 27.3% (n=6) of the allogeneic group and 64.3% (n=9) of the autologous group watched it 5-6 days/week. Almost 32% (n=7) of the allogeneic group and 28.6% (n=4) of the autologous group watched television 3-4 days/week. Only 1 participant (4.5%) from the allogeneic group and none of the autologous group said they watched it 1-2 days/week. Similarly, only one participant (7.1%) from the autologous group said they never watched television (table 6.52).

Table 6.52 How often TV was turned on

**Q30 TV \* Allo/Auto Crosstabulation**

			Allo/Auto		Total
			Auto	Allo	
Q30 TV	Always (Every day)	Count	0	8	8
		% within Allo/Auto	.0%	36.4%	22.2%
	Often (5-6 days/wk)	Count	9	6	15
		% within Allo/Auto	64.3%	27.3%	41.7%
	Sometimes (3-4 days/wk)	Count	4	7	11
		% within Allo/Auto	28.6%	31.8%	30.6%
	Seldom (1-2 days/wk)	Count	0	1	1
		% within Allo/Auto	.0%	4.5%	2.8%
	Never	Count	1	0	1
		% within Allo/Auto	7.1%	.0%	2.8%
Total		Count	14	22	36
		% within Allo/Auto	100.0%	100.0%	100.0%

These results indicate that overall those in the allogeneic group had a more positive experience of ‘Open Window’. This could be attributed to the duration of their time in isolation was much longer than the autologous group.

When interviewed six months after their transplant many of the participants reported that they did not often think of ‘Open window’ as it reminded them of the Denis Burkitt Unit which they associated with a difficult time in their lives, and were subsequently trying to forget. Others felt that although they had thought about ‘Open Window’ on occasion, it did not increase or stimulate their interest in art.

- “I kind of package it in with the whole sort of atmosphere [in the Denis Burkitt Unit] then that I try not to think about”.  
Documents\Allo Intervention Group A\T7\A1027IntT7
- “I haven’t thought about it for a while now but I did think about it after the hospital but not really any more now”.  
Documents\Allo Intervention Group A\T7\A1033IntT7

Six participants felt that their experience of 'Open Window' had a positive influence on their interest in art, and even so long after their experience they still had thoughts about what familiar images they would like to have seen on the screen (Appendix 20).

- "Q Do you feel that you are more aware of art now or scenes of nature?

A: Yeah I'm inclined to stop up or watch it... we went to Tipperary yesterday and walked down the town and in the window there was, it was amazing, there was about four paintings in a window and I stopped and there was one with roses and another with flowers along a drive way and it was very unusual and I was thinking about 'Open Window'."

Documents\Auto Intervention Group C\T7\Au030IntT7

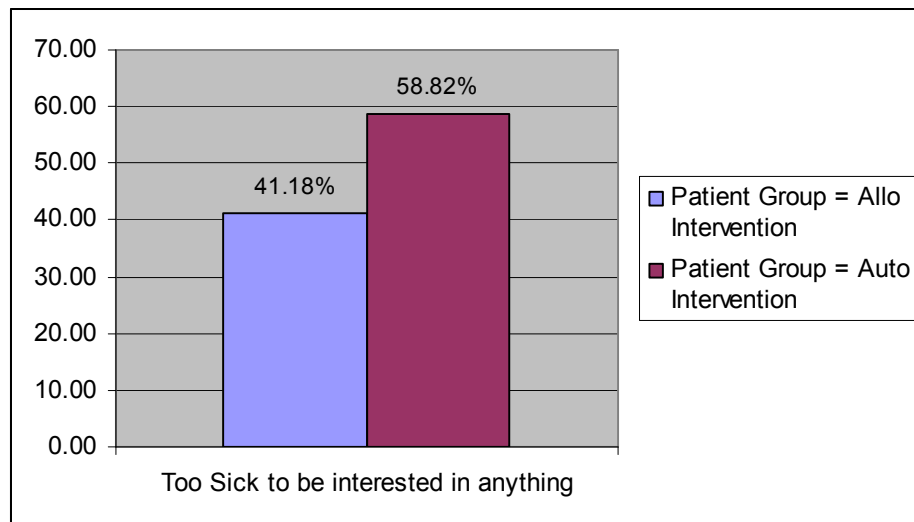
- "Q: Do you ever think about it [Open Window]?"

A: Well I have thought about it many a time and I have thought how stupid I was to ask for that place up there and all the lovely places at home... I should have said Mullraney or Westport, its gorgeous out there."

Documents\Allo Intervention Group A\T7\A1022IntT7

It was interesting to note that even though the percentage of those who watched television was a little higher than those who used 'Open Window' on a daily basis, the differences are not dramatic. One of the main reasons why 'Open Window' or indeed the television was not used on a daily basis was that most participants experienced intense adverse physical symptoms due to side effects of their medication. Qualitative data supports this view with 18 participants out of a total of 36 commenting that they had no interest in anything, even visitors because they were so sick physically (figure 6.6).

Figure 6.6 Too Sick to be Interested in Anything



- “I think I was just too zonked out to care about anything really”.  
Documents\Allo Intervention Group A\T4\A1023\IntT4
- “I was in my own little bubble which was my bed and plugged in to that machine, and just, just trying to survive what was being thrown at me you know, I hardly, read a paper, I hardly looked at the television!”  
Documents\Allo Intervention Group A\T4\A1027\IntT4

Two primary functions of ‘Open Window’ were to provide patients with a relaxing and soothing environment; and to provide an environment conducive to self-reflection. Participants expressed negative (n=38) (figure 6.7) and positive (n=22) (figure 6.8) feelings about the room and its effect on them. Negative comments centered on feelings of boredom, and isolation. Positive comments centered on feelings of contentment or happiness because the room was quiet, clean, bright and private. The responses from males and females are proportional to sample representation, therefore, do not suggest differences in negative or

positive feelings. In relation to the differences between the sample groups, collectively the intervention samples reported more positive feelings towards their environment (n=16) than the control group (n=6) (figure 6.8). Both sample groups made a similar number of negative comments (n=20 for the intervention groups and 18 for the control groups) (figure 6.7).

Figure 6.7 Negative feelings about the room by group and by gender

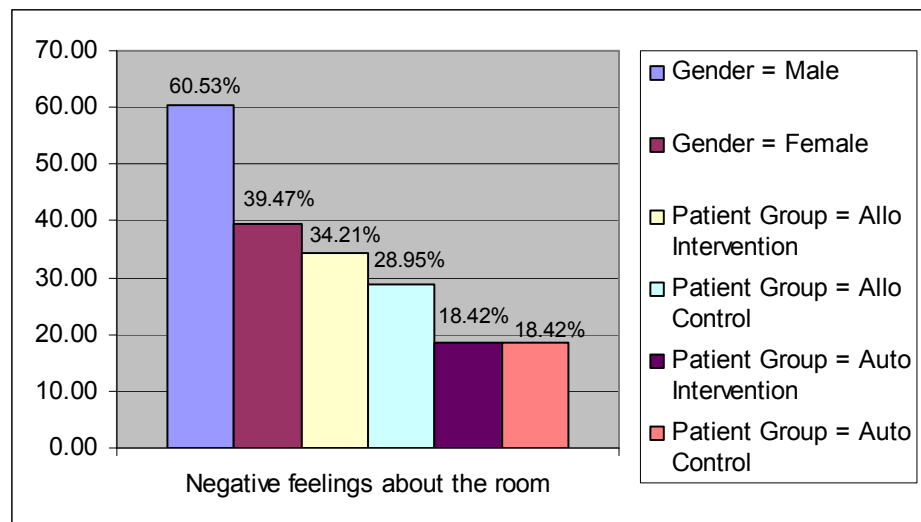
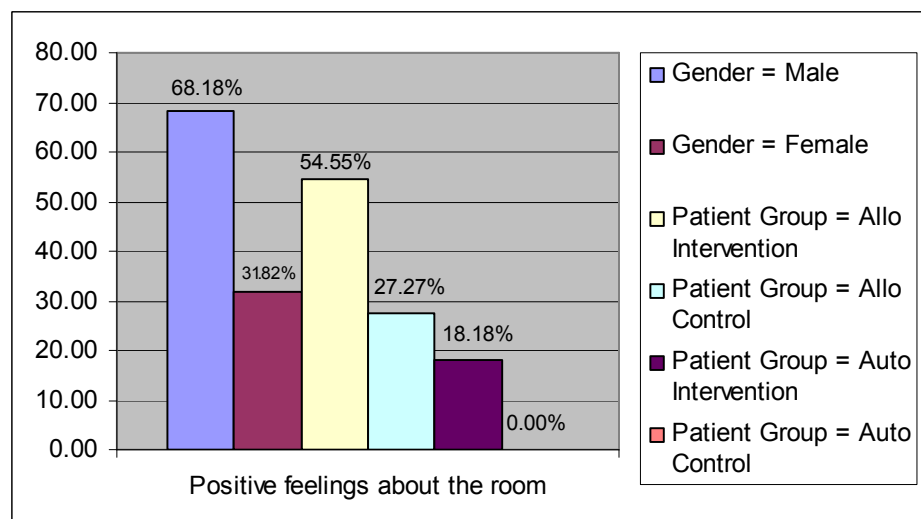


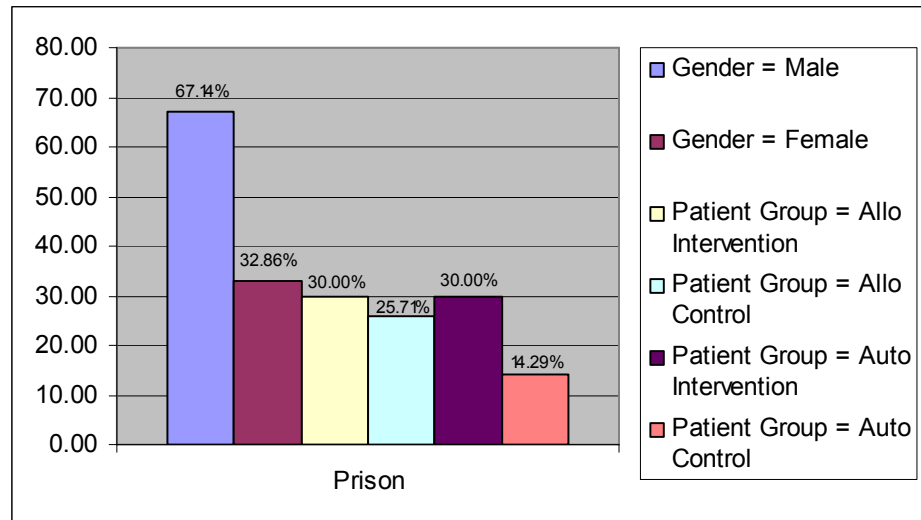
Figure 6.8 Positive feelings about the room by group and by gender



Participants in this study frequently used the word prison to describe their environment with 65 coding sources and 141 coding references (Appendix 21).

No particular sample group or gender seemed to feel this way about the environment, it was a comment made by participants from all groups (figure 6.9). This was attributed to the isolation, confinement and restrictions.

Figure 6.9 It's like a prison



However, while describing it as a prison many also pointed out that it made them feel safe from infection and it was where they needed to be.

- “yeah I was isolated but I had a function I knew why, the whole point of the isolation so I mean it wasn't the case of I mean being frustrated by it I knew the function of it but it's obviously to do with the health and infection and that so I had the supporters and I was quite fine with that anyway”.

Documents\Allo Control Group B\T7\A1025CT7

- “Basically you're in solitary confinement, you know, but then again I understand from a disease point of view, you know, when your blood counts go down, it's all in your own interest”.

Documents\Auto Control Group D\T4\Au010 C T4

This is supported by the number of participants that commented on the feeling of safety that the room gave them. This feeling related primarily to the reduced risk of infection and meeting their needs.

- “No, it [the room] doesn’t have a negative effect, no definitely not ... what you need is in it and it’s clean and it’s effective”  
Documents\Allo Intervention Group A\T1\AI014 Int T1
- “Sometimes I go out there and it’s a little bit of a relief to come back here like, like last week somebody was taking me out the door for an X-ray and I was panicking because I knew my counts [white blood cells] were a bit down ... I was just so glad, I nearly cried when I got back here”.  
Documents\Allo Intervention Group A\T4\AI037IntT4

When asked if they would change the room in any way, participants generally commented on practical issues such as the lack of a shower curtain or the TV being too small. Aesthetic issues were equally targeted, for example, some commented on the need for more colour in the room or a picture on the wall (Appendix 19a)

When interviewed at T7 the majority of participants reported that they had very positive memories of their environment (n=37). Quite a high number also said they had negative memories of the room (n=29). The issues contributing to whether the environment was remembered positively or negatively were the same as when the participants were receiving treatment in the Denis Burkitt Unit. Positive comments centered on the room being bright, clean and safe and negative comments related to feelings of isolation, and rooms being small, or dark (Appendix 19a).

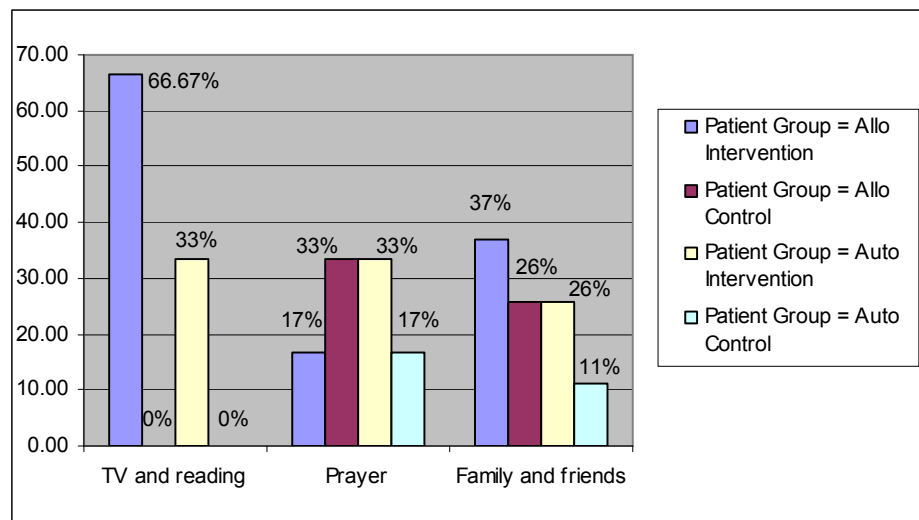


## 6.6 Hospital Anxiety and Depression Scale and Distress Thermometer

The main cause of anxiety, depression and distress in patients with cancer is stress and loss of control. Exploration of the qualitative data provides a context and explanation for the impact of stress and control issues on participant reported levels of anxiety, depression and distress over time, therefore will be presented before giving results of the questionnaires.

Qualitative data indicated that 48 participants experienced stress at some stage during their treatment and recovery, and 20 participants said they did not. Appendix 19e shows that participants referred to their experiences of stress frequently with 88 references and 55 respectively. Those that experienced stress described it as episodic and related to particular physical symptoms, side effects of medication and concern about their recovery. Family and friends were identified as the greatest support in helping participants deal with stress (n=27), with a small number of participants including prayer (n=6) or TV (n=3) and reading as helpful (Figure 6.10). A small number (n=13) said that they responded to stress in this situation as they did in their lives before they became ill; this included responses such as using humour or ‘getting on with it’.

Figure 6.10 Dealing with Stress – Sources of Support



Perceived level of control over their lives and decisions affecting their lives is also a factor in increasing levels of anxiety, depression and distress in cancer patients (Fife et al. 2000, Xuereb and Dunlop 2003). The qualitative data in this study revealed that about one third (n=48) of the participants perceived that they had control over their lives, the same number (n=48) said they did not have control and a slightly lower number (n=42) felt they had some control (figure 6.11).

Figure 6.11 Perceptions of control

	I have control	I have no control	I have some control
Allogeneic Intervention	(9) 18.75%	(13) 27.08%	(16) 33.33%
Allogeneic Control	(10) 20.83%	(18) 37.50%	(8) 16.67%
Autologous Intervention	(19) 39.58%	(9) 18.75%	(7) 14.58%
Autologous Control	(10) 20.83%	(8) 16.67%	(11) 22.92%

Most of those who said they did not have control were quite pragmatic about it in that it was something they had to put up with in order to get better. They believed that the treatment required to recover from cancer was outside their control.

- “I have no choice in the matter it’s just there, I’m sick, I have cancer, I want to get rid of it so this is it!”  
Documents\Auto Control Group D\T1\Au026CT1
- “I think it’s an eye opener that you are such a small part of a very large universe and I’m not saying people are unimportant but for want of a better word that is what we are. No matter how rich, brainy or what ever you are, if you get an illness it’s all the same, it’s up to the doctors, these are the people that can help or not, that’s it!”  
Documents\Allo Control Group B\T1\AI013CT1

- I accept what's being done but I also realise that I still have no control over it I mean if works, it works! I am very hopeful that it will work but if it doesn't work I don't know that I can physically make it work and as much as I want to I don't know if there's anything I can do physically or even mentally do you know I mean we talk about this fight cancer and (inaudible) was saying to myself 'how do I fight it you know' it's up to the medicines that they're giving me if they work, they work"

Documents\Allo Intervention Group A\T1\A1037IntT1

- "Well there is nothing you could do, you have to stay here and get your medicine and you've two choices get your medicine or die, so you're best off getting your medicine really".

Documents\Auto Control Group D\T4\Au011 C T4

Others said they did not mind not having control because the doctors and nurses knew best.

- "I see it like there's no point in me sitting down and telling the doctors 'well look at this is what I think' they should do you know they're the people that know so I'm leaving it up to them to for them to say 'look at this is what you need now you have to get this after the other like you know"

Documents\Auto Control Group D\T4\Au027CT4

Participants commented that they trusted the medical and nursing staff and others indicated that the relationship they had with medical/nursing staff was influential in their emotional state. Positive interpersonal communication seemed to reassure patients and made them feel cared for.

- "Being the focus of something is an unusual experience because you suddenly realise you have a huge team out there looking after you. I

didn't realise the amount of liaison that was going on until I came over here to be harvested. When I arrived here they all knew me because they had been discussing me all the time whereas I never met any of these people before... that made me feel special"

Documents\Allo Control Group B\T1\AL035CT1

- "Like the nurses were so sound and so were the doctors, they come in and sit down and talk as I talk to you, as if there are just two ordinary people talking about it... That's how you trust them because you know they are going to do their best for you and they are telling you and they treat me that way you know... This person is going to do the very best they can for me"

Documents\Allo Intervention Group A\T1\AI024IntT1

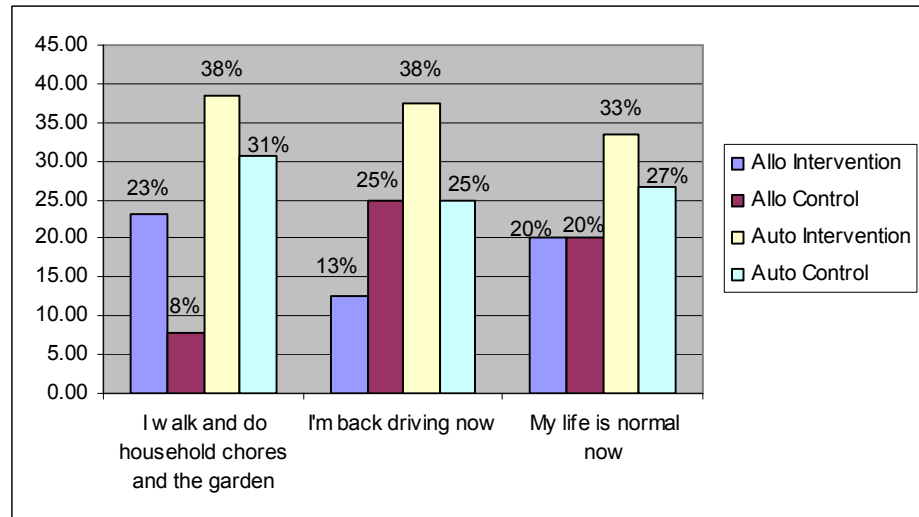
Participants commented on the value of positive interpersonal relations with nurses but some seemed frustrated by the frequent changes in staffing. Others felt that as a result of poor communication, they did not feel cared for as individuals (Appendix 19).

- "You have a different nurse every day you have no relationship with any nurses... you think you have built up a relationship, you have a nurse for two days and she's gone... It would be nice to be able to have a bit of fun or whatever ..."

Documents\Auto Control Group D\T4\Au026CT4>

One of the most important goals of participants seemed to be the need to return to 'normal' life. At T7 participants indicated recovery after the transplant was associated with achievement of 'normal' activities, such as driving, walking and household or garden activities with some participants just referring to how their lives were now normal (figure 6.12).

Figure 6.12 'Normal Life'



- “Last week I must say I felt great, after the walk when I came back and had a shower you know and it was that and the feel back to myself you know”.

Documents\Allo Intervention Group A\T7\A1038IntT7

- “I tip away in the morning and I hang out the washing now, I make two or three trips to the clothes line and it keeps me going and I walk in and out of town so I get a bit of fresh air as well”.

Documents\Auto Intervention Group C\T7\Au030IntT7

- “I kind of go off to town on my own now but I couldn’t in the beginning when I first went home ... I was very tired and that and I wasn’t back driving either so as soon as I got back driving, I went to town (laughing)”.

Documents\Auto Control Group D\T7\Au020CT7

A small number of participants (n=13) felt that they could never have full control over their lives again because of the constant worry or fear that it would return.

This feeling did not prevail in any particular group according to type of transplant, gender or age, although there is evidence from the number of word references in the qualitative data, females were more expressive on this topic than males (Figure 6.13).

Figure 6.13 Fear that Disease will return

	Disease will come back
Male	46.15% (319)
Female	53.85% (572)
Allogeneic Intervention	23.08% (200)
Allogeneic Control	23.08% (250)
Autologous Intervention	15.38% (91)
Autologous Control	38.46% (350)

*\*Numbers in blue refer to number of word references*

Another common response to the diagnosis of a life threatening illness is a weak sense of ‘self’. This has the effect of reducing self esteem which subsequently influences how individuals respond to stress and control issues. One of the new themes that emerged from this study was ‘*Self and Others*’. During phase one coding and formation of the main template it was observed that participants, when asked if they had learned anything about themselves or their relationship with others during their experience of being diagnosed with cancer and undergoing stem cell or bone marrow transplantation, frequently responded in positive terms. They expressed surprise at how well they responded, mentally, physically and emotionally, to the diagnosis, treatment and recovery. This inner strength in conjunction with the always very positively reported relationships with family and sometimes friends seemed to be key factors in how participants experienced and dealt with having cancer and being treated for it (Appendix 19d).

- “it [relationship with family] changed completely, in a good way in one sense because it showed the strength of my children and my husband like that they really have showed me what kind of people they are, they have

been so supportive and so caring to me ... after coming home, it has been wonderful to see what they did and what they do and what they've done for me”

Documents\Allo Control Group B\T1\AL040CT1

The qualitative findings presented in this chapter are intended to provide a context and explanation for the findings of the psychometric tools, the HADS and DT.

6.6.1 Overall scores for Anxiety, Depression and Distress between the groups  
 The results from these two psychometric tools are presented under the same heading as the content and outcomes are interrelated and this will provide a clearer picture of the overall psychological morbidity of the participants and possible effect of ‘Open Window’. In the autologous group the mean overall score for the HADS across all the time points for anxiety was 6, and for depression, was 4. In the allogeneic group the mean overall score across all the time points for anxiety was slightly lower at 5 and for depression was also 4 (table 6.53). There were no differences between the autologous and the allogeneic group in relation to the scores on the DT with 4 being the mean, 2 for percentile 25 and 6 for percentile 75 (tables 6.53 and 6.54).

Table 6.53 Scores for anxiety and depression in allogeneic and autologous groups

Scores Anxiety and Depression							
AutoAllo		Valid N	Minimum	Mean	Median	Maximum	Std Deviation
Auto	Anxiety	N=197	0	6	6	18	3
	Depression	N=197	0	4	3	18	3
Allo	Anxiety	N=270	0	5	4	17	3
	Depression	N=270	0	4	2	16	3

Table 6.54 Scores for distress in the allogeneic and autologous groups

Q1 Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

AutoAllo	Valid N	Minimum	Percentile 25	Mean	Median	Percentile 75	Maximum
Auto Q1 Circle the number(0-10) that best describes how much distress you have been experiencing in the past week including today	N=194	0	2	4	4	6	10
Allo Q1 Circle the number(0-10) that best describes how much distress you have been experiencing in the past week including today	N=267	0	2	4	3	6	10

The problem list identified many similarities in the issues that caused distress across both groups. Over 95% of those in the autologous and allogeneic group indicated that practical issues, such as childcare, housing, insurance, transport and work were not a problem. Almost the same percentage in both groups said that family issues and spiritual/religious concerns were not a problem. Emotional and physical problems seemed to be the main cause of distress. In relation to the emotional issues, 31.1% (n=61) of the autologous group and 19.2% (n=51) of the allogeneic group indicated that depression was a problem for them. A higher percentage indicated that fears were a cause of distress with 63.8% (n=125) of the autologous group and 46.6% (n=124) of the allogeneic group indicating this. A similar number of participants said that nervousness was a cause of distress with 55.9% (n=109) of the autologous group and 47% (n=125) of the allogeneic group indicating this. A smaller percentage of 34% (n=66) of the autologous group and 27.2% (n=72) of the allogeneic said that sadness was a cause of distress. Worry seemed to cause the most distress with 70.9% (n=139) and 63.7% (n=170) indicating this (tables 6.55). The physical problems that were ranked highest by both groups as causing distress were, starting with the highest percentage, eating, fatigue, sleep, nausea, diarrhoea, getting around and being swollen in decreasing order (table 6.55).



Table 6.55 Main Causes of Distress

		Yes	No
Depression	Auto	61 (31.1%)	135 (68.9%)
	Allo	51 (19.2%)	214 (80.8%)
	<b>Total</b>	<b>112 (24.3%)</b>	<b>349 (75.7%)</b>
Fears	Auto	125 (63.8%)	71 (36.2%)
	Allo	124 (46.6%)	142 (53.4%)
	<b>Total</b>	<b>249 (53.9%)</b>	<b>213 (46.1%)</b>
Nervousness	Auto	109 (55.9%)	86 (44.1%)
	Allo	125 (47%)	141 (53%)
	<b>Total</b>	<b>234 (58.8%)</b>	<b>227 (49.2%)</b>
Sadness	Auto	66 (34%)	128 (66%)
	Allo	72 (27.2%)	193 (72.8%)
	<b>Total</b>	<b>138 (30.1%)</b>	<b>321 (69.9%)</b>
Worry	Auto	139 (70.9%)	57 (29.1%)
	Allo	170 (63.7%)	97 (36.3%)
	<b>Total</b>	<b>309 (66.7%)</b>	<b>154 (33.3%)</b>
Diarrhoea	Auto	51 (26%)	145 (74%)
	Allo	61 (22.8%)	206 (77.2%)
	<b>Total</b>	<b>112 (24.2%)</b>	<b>351 (75.8%)</b>
Eating	Auto	86 (43.9%)	110 (56.1%)
	Allo	121 (45.3%)	146 (54.7%)
	<b>Total</b>	<b>207 (44.7%)</b>	<b>256 (55.3%)</b>
Fatigue	Auto	123 (62.8%)	73 (37.2%)
	Allo	164 (61.4%)	103 (38.6%)
	<b>Total</b>	<b>287 (62%)</b>	<b>176 (38%)</b>
Feeling swollen	Auto	22 (11.2%)	174 (88.8%)
	Allo	68 (25.6%)	198 (74.4%)
	<b>Total</b>	<b>90 (19.5%)</b>	<b>372 (80.5%)</b>
Getting around	Auto	43 (21.9%)	153 (78.1%)
	Allo	54 (20.3%)	212 (79.7%)
	<b>Total</b>	<b>97 (21%)</b>	<b>365 (79%)</b>
Nausea	Auto	67 (34.2%)	129 (65.8%)
	Allo	69 (26%)	196 (74%)
	<b>Total</b>	<b>136 (29.5%)</b>	<b>325 (70.5%)</b>
Pain	Auto	32 (16.3%)	164 (83.7%)
	Allo	57 (21.4%)	209 (78.6%)
	<b>Total</b>	<b>89 (19.3%)</b>	<b>373 (80.7%)</b>
Sleep	Auto	73 (37.4%)	122 (62.6%)
	Allo	97 (36.3%)	170 (63.7%)
	<b>Total</b>	<b>170 (36.8%)</b>	<b>292 (63.2%)</b>

### 6.6.2 Scores by Allocation Group

When these results of the HADS for the autologous and allogeneic groups are broken down by allocation, that is, intervention and control there is only a slight difference between the overall mean scores and the intervention and control groups. The mean score of the autologous intervention group for anxiety is 6 and for depression is 4. The control group has the same mean score of 6 for anxiety and a slightly higher score of 5 for depression (table 6.56). The mean score of the allogeneic intervention group for anxiety is 5 and depression is 3. The control group has the same mean score of 5 for anxiety and a slightly higher score of 4 for depression (table 6.57).

When the results of the DT for the autologous and allogeneic groups are broken down by allocation, again there is minimal difference between the overall mean scores and the intervention and control groups. The mean score of the autologous intervention group is 4, the percentile 25 is 2 and the percentile 75 is 5. The control group score is the same except for the slightly higher distress score of 6 in percentile 75 (table 6.58). Similarly the mean score of the allogeneic intervention group is 4, the percentile 25 is 2 and percentile 75 has a slightly higher score for distress at 6 than the autologous group. The control group have the same scores with a mean score of 4, a percentile 25 of 2 and percentile 75 of 6 (table 6.59).

Table 6.56 Mean scores for anxiety/depression in the intervention and control samples from the autologous group

Scores Anxiety and Depression							
Allocation		Valid N	Minimum	Mean	Median	Maximum	Std Deviation
Intervention	Anxiety	N=93	0	6	5	18	4
	Depression	N=93	0	4	2	15	3
Control	Anxiety	N=104	0	6	6	14	3
	Depression	N=104	0	5	4	18	3

Table 6.57 Mean scores for anxiety/depression in the intervention and control samples from the allogeneic group

**Scores Anxiety and Depression**

Allocation		Valid N	Minimum	Mean	Median	Maximum	Std Deviation
Intervention	Anxiety	N=151	0	5	4	17	3
	Depression	N=151	0	3	2	15	3
Control	Anxiety	N=119	0	5	5	13	3
	Depression	N=119	0	4	3	16	4

Table 6.58 Mean score for distress in the intervention and control samples from the autologous group

**Q1 Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.**

Allocation		Valid N	Minimum	Percentile 25	Mean	Median	Percentile 75	Maximum
Intervention	Q1 Circle the number(0-10) that best describes how much distress you have been experiencing in the past week including today	N=93	0	2	4	4	5	10
Control	Q1 Circle the number(0-10) that best describes how much distress you have been experiencing in the past week including today	N=101	0	2	4	4	6	10

Table 6.59 Mean score for distress in the intervention and control samples from the allogeneic group

**Q1 Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.**

Allocation		Valid N	Minimum	Percentile 25	Mean	Median	Percentile 75	Maximum
Intervention	Q1 Circle the number(0-10) that best describes how much distress you have been experiencing in the past week including today	N=149	0	2	4	3	6	10
Control	Q1 Circle the number(0-10) that best describes how much distress you have been experiencing in the past week including today	N=118	0	2	4	3	6	9

### 6.6.3 Repeated measures ANOVA for Allogeneic / Autologous Groups

#### 6.6.3.1 Anxiety

SPSS tests to see if it is acceptable to perform an ANOVA on data using the Mauchly's test of sphericity, that is, if the data satisfy relevant assumptions. Looking at anxiety, the Mauchly's Sphericity test is not significant ( $p=.432$ ) (table 6.60) therefore this test is appropriate when considering within-subject effects for anxiety.

Table 6.60 Mauchly's Test of Sphericity for anxiety across the groups

**Mauchly's Test of Sphericity<sup>b</sup>**

Measure: MEASURE\_1

Within Subjects Effect	Mauchly's W	Approx. Chi-Square	df	Sig.	Epsilon <sup>a</sup>		
					Greenhouse e-Geisser	Huynh-Feldt	Lower-bound
Anxiety	.698	20.439	20	.432	.910	1.000	.167

Tests the null hypothesis that the error covariance matrix of the orthonormalized transformed dependent variables is proportional to an identity matrix.

a. May be used to adjust the degrees of freedom for the averaged tests of significance. Corrected tests are displayed in the Tests of Within-Subjects Effects table.

b.

Design: Intercept+Allocation  
Within Subjects Design: Anxiety

The test of 'within-subjects effects' and the row 'Anxiety' respond to the null hypothesis that anxiety is constant over time. In this instance the Mauchly's Sphericity test is significant ( $p=.000$ ), this indicates that the null hypothesis is rejected and levels of anxiety change over time (table 6.61). In the same table, the row 'Anxiety\*Allocation' responds to the hypothesis that intervention and control samples do not mix over time. The sphericity-assumed test is not statistically significant ( $p=.082$ ), therefore, the hypothesis is accepted, intervention and control samples do not exhibit different trends in relation to levels of anxiety over time (table 6.61).

Table 6.61 Test of ‘within-subjects effects’ for anxiety across the groups

**Tests of Within-Subjects Effects**

Measure: MEASURE\_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig.
Anxiety	Sphericity Assumed	203.159	6	33.860	6.113	.000
	Greenhouse-Geisser	203.159	5.460	37.211	6.113	.000
	Huynh-Feldt	203.159	6.000	33.860	6.113	.000
	Lower-bound	203.159	1.000	203.159	6.113	.016
Anxiety * Allocation	Sphericity Assumed	62.700	6	10.450	1.887	.082
	Greenhouse-Geisser	62.700	5.460	11.484	1.887	.090
	Huynh-Feldt	62.700	6.000	10.450	1.887	.082
	Lower-bound	62.700	1.000	62.700	1.887	.175
Error(Anxiety)	Sphericity Assumed	1960.682	354	5.539		
	Greenhouse-Geisser	1960.682	322.116	6.087		
	Huynh-Feldt	1960.682	354.000	5.539		
	Lower-bound	1960.682	59.000	33.232		

In the table ‘Tests of Between-Subjects Effects’ the row ‘Allocation’ responds to the hypothesis that the intervention and control samples are similar over time. The test is not statistically significant ( $p=.328$ ), therefore, the hypothesis is accepted that the mean score for anxiety for the intervention and control samples in the allogeneic and autologous groups is not different over time (table 6.62). Confidence intervals shown in table 6.63 for each time point indicate that although levels of anxiety change over time, there is considerable overlap in estimated mean scores for the intervention and control samples.

Table 6.62 Tests of Between-Subjects Effects for anxiety across the groups

**Tests of Between-Subjects Effects**

Measure: MEASURE\_1  
Transformed Variable: Average

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	12459.307	1	12459.307	301.100	.000
Allocation	40.291	1	40.291	.974	.328
Error	2441.376	59	41.379		

Table 6.63 Confidence Intervals for anxiety across the groups

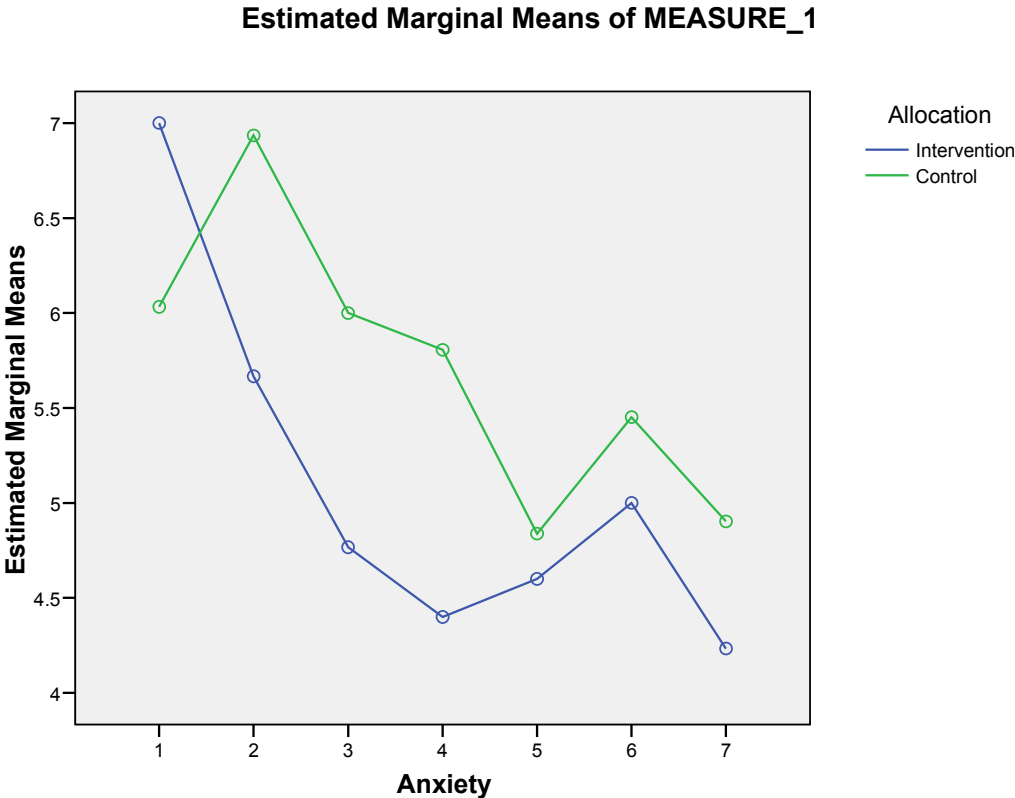
**Allocation \* Anxiety**

Measure: MEASURE\_1

Allocation	Anxiety	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
Intervention	1	7.000	.663	5.674	8.326
	2	5.667	.590	4.486	6.848
	3	4.767	.564	3.638	5.896
	4	4.400	.606	3.187	5.613
	5	4.600	.607	3.386	5.814
	6	5.000	.639	3.722	6.278
	7	4.233	.488	3.256	5.210
Control	1	6.032	.652	4.728	7.336
	2	6.935	.581	5.774	8.097
	3	6.000	.555	4.889	7.111
	4	5.806	.596	4.614	6.999
	5	4.839	.597	3.645	6.033
	6	5.452	.628	4.195	6.709
	7	4.903	.480	3.942	5.864

Figure 6.14 shows the estimated marginal means for levels of anxiety over the seven time points for the intervention and control samples from both groups. The overall trend suggests that the intervention group have lower levels of anxiety than the control group at all data collection points with the exception of T1. The difference in scores between the groups, however, is never more than 2 points.

Figure 6.14 Estimated marginal means for anxiety across the groups over 7 time points



6.6.3.2 Depression

Mauchly's Test of Sphericity is significant ( $p=.002$ ) for depression (table 6.64). This means that this test will be disregarded when considering within subject effects.

Table 6.64 Mauchly's Test of Sphericity for depression across the groups

**Mauchly's Test of Sphericity<sup>b</sup>**

Measure: MEASURE\_1

Within Subjects Effect	Mauchly's W	Approx. Chi-Square	df	Sig.	Epsilon <sup>a</sup>		
					Greenhouse-Geisser	Huynh-Feldt	Lower-bound
Depression	.471	42.726	20	.002	.824	.924	.167

Tests the null hypothesis that the error covariance matrix of the orthonormalized transformed dependent variables is proportional to an identity matrix.

a. May be used to adjust the degrees of freedom for the averaged tests of significance. Corrected tests are displayed in the Tests of Within-Subjects Effects table.

b.

Design: Intercept+Allocation  
 Within Subjects Design: Depression

The test of 'within-subjects effects' and the row 'Depression' responds to the null hypothesis that depression is constant over time. In this instance as Mauchly's Sphericity test is not appropriate, therefore, the Greenhouse-Geisser test was used. This test is significant ( $p=0.000$ ) which indicates that the null hypothesis is rejected and levels of depression change over time (table 6.65). In the same table, the row 'Anxiety\*Allocation' responds to the hypothesis that intervention and control samples do not mix over time. The Greenhouse-Geisser test is not statistically significant ( $p=.117$ ), therefore, the hypothesis is accepted, intervention and control samples do not exhibit significantly different trends in relation to levels of depression over time (table 6.65).

Table 6.65 Tests of within-subjects effects for depression across the groups

**Tests of Within-Subjects Effects**

Measure: MEASURE\_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig.
Depression	Sphericity Assumed	604.528	6	100.755	13.890	.000
	Greenhouse-Geisser	604.528	4.944	122.284	13.890	.000
	Huynh-Feldt	604.528	5.542	109.088	13.890	.000
	Lower-bound	604.528	1.000	604.528	13.890	.000
Depression * Allocation	Sphericity Assumed	77.511	6	12.919	1.781	.102
	Greenhouse-Geisser	77.511	4.944	15.679	1.781	.117
	Huynh-Feldt	77.511	5.542	13.987	1.781	.108
	Lower-bound	77.511	1.000	77.511	1.781	.187
Error(Depression)	Sphericity Assumed	2567.795	354	7.254		
	Greenhouse-Geisser	2567.795	291.675	8.804		
	Huynh-Feldt	2567.795	326.959	7.854		
	Lower-bound	2567.795	59.000	43.522		



In the table ‘Tests of Between-Subjects Effects’ the row ‘Allocation’ responds to the hypothesis that the intervention and control samples are similar over time. The test is not statistically significant ( $p=.028$ ), therefore, the hypothesis is accepted that the mean score for depression for the intervention and control groups is not significantly different over time (table 6.66). Confidence intervals shown in table 6.67 for each time point indicate that although levels of depression change over time and this is significant in the intervention group at T3, there is considerable overlap in estimated mean scores within and between intervention and control samples at all other time points.

Table 6.66 Tests for between-subjects effects for depression across the groups

**Tests of Between-Subjects Effects**

Measure: MEASURE\_1

Transformed Variable: Average

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	6789.046	1	6789.046	230.293	.000
Allocation	149.964	1	149.964	5.087	.028
Error	1739.320	59	29.480		

Table 6.67 Confidence intervals for depression across the groups

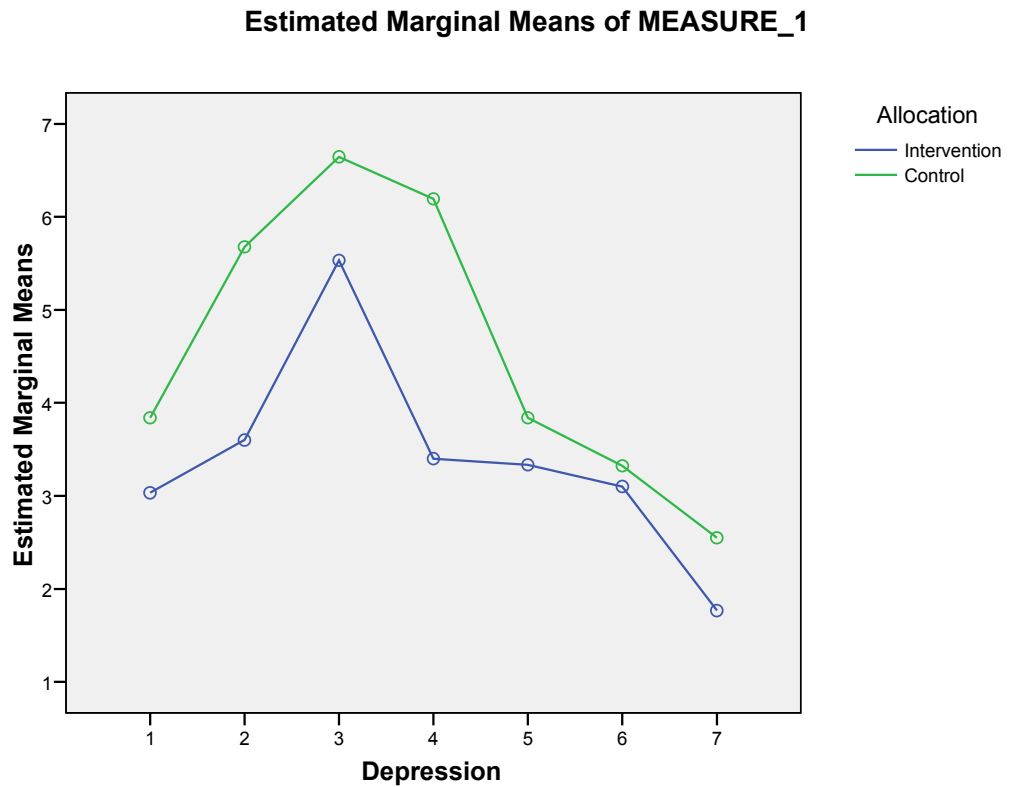
**Allocation \* Depression**

Measure: MEASURE\_1

Allocation	Depression	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
Intervention	1	3.033	.438	2.157	3.909
	2	3.600	.694	2.212	4.988
	3	5.533	.746	4.041	7.026
	4	3.400	.736	1.928	4.872
	5	3.333	.486	2.360	4.307
	6	3.100	.538	2.024	4.176
	7	1.767	.371	1.025	2.508
Control	1	3.839	.431	2.977	4.700
	2	5.677	.683	4.312	7.043
	3	6.645	.734	5.177	8.113
	4	6.194	.724	4.745	7.642
	5	3.839	.479	2.881	4.796
	6	3.323	.529	2.264	4.381
	7	2.548	.365	1.819	3.278

Figure 6.15 shows the estimated marginal means for levels of depression over the seven time points for the intervention and control groups. The highest level of depression seen in both groups is T3, however the control group have higher levels of depression at T2 and T4 with a marked difference in scores of 3 points.

Figure 6.15 Estimated marginal means for depression across the groups over 7 time points



6.6.3.3 Distress

Mauchly's Test of Sphericity is not significant ( $p=.912$ ) for distress (table 6.68). This means that this test will be relevant when considering within subject effects.

Table 6.68 Mauchly's Test of Sphericity for distress across the groups

Measure: MEASURE_1							
Within Subjects Effect	Mauchly's W	Approx. Chi-Square	df	Sig.	Epsilon <sup>a</sup>		
					Greenhouse-Geisser	Huynh-Feldt	Lower-bound
Distress	.795	12.119	20	.912	.931	1.000	.167

Tests the null hypothesis that the error covariance matrix of the orthonormalized transformed dependent variables is proportional to an identity matrix.

a. May be used to adjust the degrees of freedom for the averaged tests of significance. Corrected tests are displayed in the Tests of Within-Subjects Effects table.

b.  
Design: Intercept+Allocation  
Within Subjects Design: Distress

The test of ‘within-subjects effects’ and the row ‘Distress’ responds to the null hypothesis that it is constant over time. In this instance the Mauchly’s Sphericity test is significant ( $p=.000$ ), this indicates that the null hypothesis is rejected and levels of anxiety change over time (table 6.69). In the same table, the row ‘Distress\*Allocation’ responds to the hypothesis that intervention and control samples do not mix over time. The sphericity-assumed test is not statistically significant ( $p=.533$ ), therefore, the hypothesis is accepted, intervention and control samples do not exhibit different trends in relation to levels of distress over time (table 6.69).

Table 6.69 Tests of within-subjects effects for distress across the groups

**Tests of Within-Subjects Effects**

Measure: MEASURE\_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig.
Distress	Sphericity Assumed	383.276	6	63.879	12.954	.000
	Greenhouse-Geisser	383.276	5.586	68.620	12.954	.000
	Huynh-Feldt	383.276	6.000	63.879	12.954	.000
	Lower-bound	383.276	1.000	383.276	12.954	.001
Distress * Allocation	Sphericity Assumed	25.121	6	4.187	.849	.533
	Greenhouse-Geisser	25.121	5.586	4.498	.849	.526
	Huynh-Feldt	25.121	6.000	4.187	.849	.533
	Lower-bound	25.121	1.000	25.121	.849	.361
Error(Distress)	Sphericity Assumed	1627.310	330	4.931		
	Greenhouse-Geisser	1627.310	307.204	5.297		
	Huynh-Feldt	1627.310	330.000	4.931		
	Lower-bound	1627.310	55.000	29.587		

In the table ‘Tests of Between-Subjects Effects’ the row ‘Allocation’ responds to the hypothesis that the intervention and control samples are similar over time. The test is not statistically significant ( $p=.948$ ), therefore, the hypothesis is accepted that the mean score for distress for the intervention and control groups is not significantly different over time (table 6.70). Confidence intervals shown in table 6.71 for each time point indicate that although levels of distress change over time, there is considerable overlap in estimated mean scores for the intervention and control samples.

Table 6.70 Tests of between-subjects effects for distress across the groups

**Tests of Between-Subjects Effects**

Measure: MEASURE\_1  
Transformed Variable: Average

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	5852.493	1	5852.493	490.125	.000
Allocation	.051	1	.051	.004	.948
Error	656.746	55	11.941		

Table 6.71 Confidence intervals for distress across the groups

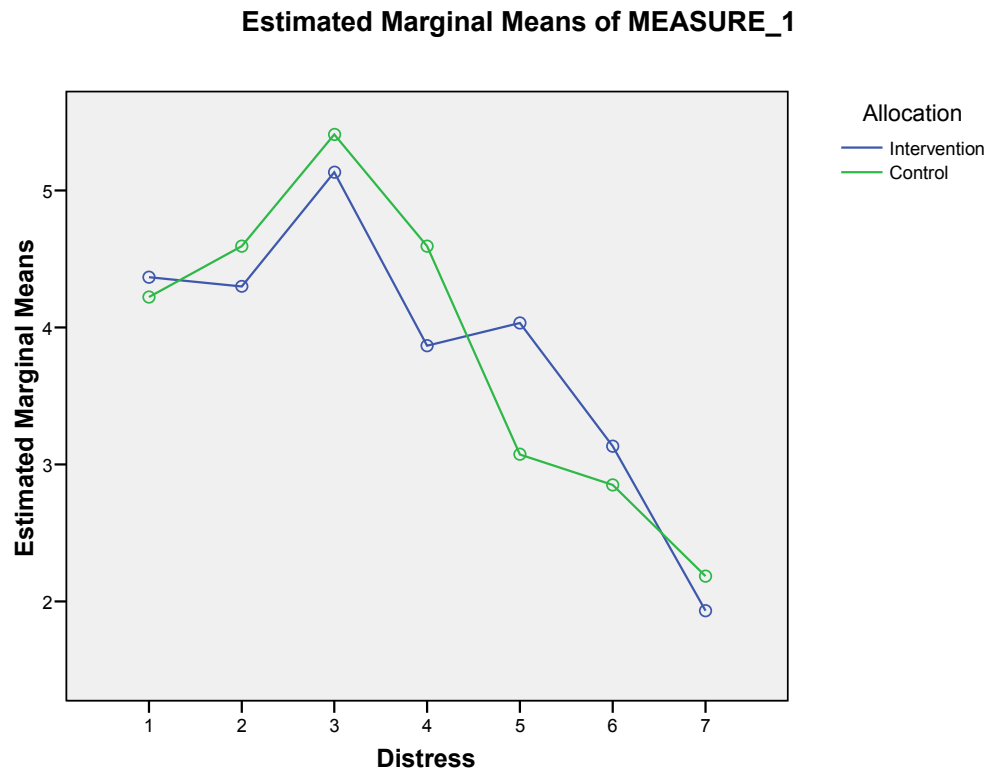
**Allocation \* Distress**

Measure: MEASURE\_1

Allocation	Distress	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
Intervention	1	4.367	.468	3.428	5.305
	2	4.300	.470	3.358	5.242
	3	5.133	.461	4.210	6.056
	4	3.867	.523	2.818	4.916
	5	4.033	.407	3.218	4.848
	6	3.133	.396	2.340	3.927
	7	1.933	.368	1.195	2.672
Control	1	4.222	.493	3.233	5.211
	2	4.593	.496	3.599	5.586
	3	5.407	.485	4.435	6.380
	4	4.593	.552	3.487	5.698
	5	3.074	.429	2.215	3.933
	6	2.852	.418	2.015	3.689
	7	2.185	.388	1.407	2.963

Figure 6.16 shows the estimated marginal means for levels of anxiety over the seven time points for the intervention and control group. There is a clear downward trend in levels of distress in both groups with the highest levels seen at T2 and T3. There is practically no difference between the levels of distress in both groups.

Figure 6.16 Estimated marginal means for distress across the groups over 7 time points



The next section looks at the differences between the intervention and control samples of the autologous and allogeneic group separately.

#### 6.6.4 Results of repeated measures ANOVA for the Autologous Group

##### 6.6.4.1 Anxiety

Mauchly's test of Sphericity is not significant ( $p=.133$ ) for Anxiety in the autologous group (table 6.72). This means that this test will be relevant when considering within subject effects.

Table 6.72 Mauchly's Test of Sphericity for Anxiety in the Autologous group

**Mauchly's Test of Sphericity<sup>b</sup>**

Measure: MEASURE\_1

Within Subjects Effect	Mauchly's W	Approx. Chi-Square	df	Sig.	Epsilon <sup>a</sup>		
					Greenhouse-e-Geisser	Huynh-Feldt	Lower-bound
Anxiety	.270	27.242	20	.133	.746	.989	.167

Tests the null hypothesis that the error covariance matrix of the orthonormalized transformed dependent variables is proportional to an identity matrix.

a. May be used to adjust the degrees of freedom for the averaged tests of significance. Corrected tests are displayed in the Tests of Within-Subjects Effects table.

b.  
Design: Intercept+Allocation  
Within Subjects Design: Anxiety

The test of 'within-subjects effects' and the row 'Anxiety' responds to the null hypothesis that anxiety is constant over time. In this instance the Mauchly's Sphericity test is significant ( $p=.007$ ), this indicates that the null hypothesis is rejected and levels of anxiety change over time (table 6.73). In the same table, the row 'Anxiety\*Allocation' responds to the hypothesis that intervention and control samples do not mix over time. The sphericity-assumed test is not statistically significant ( $p=.434$ ), therefore, the hypothesis is accepted, intervention and control samples do not exhibit significantly different trends in relation to levels of anxiety over time (table 6.73).

Table 6.73 Tests of within-subjects effects for anxiety in the autologous group

**Tests of Within-Subjects Effects**

Measure: MEASURE\_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig.
Anxiety	Sphericity Assumed	108.711	6	18.118	3.070	.007
	Greenhouse-Geisser	108.711	4.478	24.278	3.070	.016
	Huynh-Feldt	108.711	5.936	18.315	3.070	.008
	Lower-bound	108.711	1.000	108.711	3.070	.093
Anxiety * Allocation	Sphericity Assumed	35.065	6	5.844	.990	.434
	Greenhouse-Geisser	35.065	4.478	7.831	.990	.422
	Huynh-Feldt	35.065	5.936	5.907	.990	.434
	Lower-bound	35.065	1.000	35.065	.990	.330
Error(Anxiety)	Sphericity Assumed	814.432	138	5.902		
	Greenhouse-Geisser	814.432	102.987	7.908		
	Huynh-Feldt	814.432	136.520	5.966		
	Lower-bound	814.432	23.000	35.410		

In the table ‘Tests of Between-Subjects Effects’ the row ‘Allocation’ responds to the hypothesis that the intervention and control samples are similar over time. The test is not statistically significant ( $p=.349$ ), therefore, the hypothesis is accepted that the mean score for anxiety in the intervention and control groups is not significantly different over time (table 6.74). Confidence intervals shown in table 6.75 for each time point indicate that although levels of anxiety change over time, there is considerable overlap in estimated mean scores for the intervention and control samples.

Table 6.74 Tests of between-subjects effects for anxiety in the autologous group

**Tests of Between-Subjects Effects**

Measure: MEASURE\_1

Transformed Variable: Average

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	5927.433	1	5927.433	167.338	.000
Allocation	32.439	1	32.439	.916	.349
Error	814.704	23	35.422		

Table 6.75 Confidence intervals for anxiety in the autologous group

**Allocation \* Anxiety**

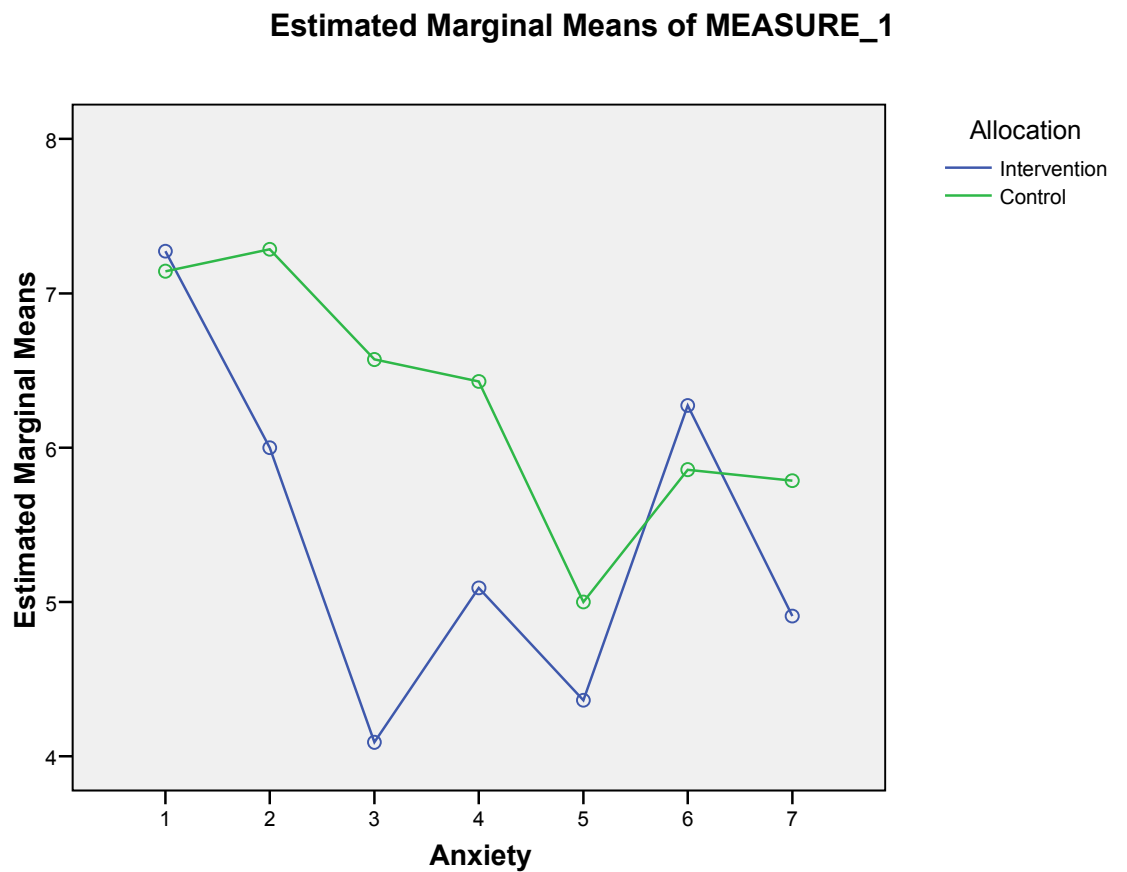
Measure: MEASURE\_1

Allocation	Anxiety	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
Intervention	1	7.273	1.103	4.991	9.555
	2	6.000	.878	4.185	7.815
	3	4.091	.776	2.486	5.696
	4	5.091	1.041	2.937	7.245
	5	4.364	.938	2.423	6.304
	6	6.273	1.159	3.875	8.670
	7	4.909	.737	3.385	6.433
Control	1	7.143	.978	5.120	9.166
	2	7.286	.778	5.676	8.895
	3	6.571	.688	5.149	7.994
	4	6.429	.923	4.519	8.338
	5	5.000	.831	3.280	6.720
	6	5.857	1.027	3.732	7.983
	7	5.786	.653	4.435	7.136



Figure 6.17 shows the estimated marginal means for levels of anxiety over the seven time points for the intervention and control samples in the autologous group. The biggest differences are seen at T2 and T3 and T4 with the intervention group showing a trend of marginally lower levels of anxiety than the control sample.

Figure 6.17 Estimated marginal means for anxiety in the autologous group over 7 time points



6.6.4.2 *Depression*

Mauchly's test of Sphericity is significant ( $p=.045$ ) for Depression in the autologous group (table 6.76). This means that this test will be disregarded when considering within subject effects.

Table 6.76 Mauchley's Test of Sphericity for depression in the autologous group

**Mauchly's Test of Sphericity<sup>b</sup>**

Measure: MEASURE\_1

Within Subjects Effect	Mauchly's W	Approx. Chi-Square	df	Sig.	Epsilon <sup>a</sup>		
					Greenhouse e-Geisser	Huynh-Feldt	Lower-bound
Depression	.214	32.072	20	.045	.654	.839	.167

Tests the null hypothesis that the error covariance matrix of the orthonormalized transformed dependent variables is proportional to an identity matrix.

a. May be used to adjust the degrees of freedom for the averaged tests of significance. Corrected tests are displayed in the Tests of Within-Subjects Effects table.

b.

Design: Intercept+Allocation  
 Within Subjects Design: Depression

The test of 'within-subjects effects' and the row 'Depression' responds to the null hypothesis that levels of depression are constant over time. In this instance as Mauchly's Sphericity test is not appropriate, therefore, the Greenhouse-Geisser test will be used. This test is significant ( $p=0.000$ ) which indicates that the null hypothesis is rejected and levels of depression change over time (table 6.77). In the same table, the row 'Depression\*Allocation' responds to the hypothesis that intervention and control samples do not mix over time. The Greenhouse-Geisser test is not statistically significant ( $p=.255$ ), therefore, the hypothesis is accepted, intervention and control samples do not exhibit significantly different trends in relation to levels of depression over time (table 6.77).

Table 6.77 Tests of within-subjects effects for depression in the autologous group

**Tests of Within-Subjects Effects**

Measure: MEASURE\_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig.
Depression	Sphericity Assumed	338.874	6	56.479	8.963	.000
	Greenhouse-Geisser	338.874	3.923	86.377	8.963	.000
	Huynh-Feldt	338.874	5.036	67.284	8.963	.000
	Lower-bound	338.874	1.000	338.874	8.963	.006
Depression * Allocation	Sphericity Assumed	51.400	6	8.567	1.360	.235
	Greenhouse-Geisser	51.400	3.923	13.102	1.360	.255
	Huynh-Feldt	51.400	5.036	10.206	1.360	.244
	Lower-bound	51.400	1.000	51.400	1.360	.256
Error(Depression)	Sphericity Assumed	869.560	138	6.301		
	Greenhouse-Geisser	869.560	90.233	9.637		
	Huynh-Feldt	869.560	115.838	7.507		
	Lower-bound	869.560	23.000	37.807		

In the table ‘Tests of Between-Subjects Effects’ the row ‘Allocation’ responds to the hypothesis that the intervention and control samples are similar over time. The test is not statistically significant ( $p=.134$ ), therefore, the hypothesis is accepted that the mean score for depression in the intervention and control autologous groups is not significantly different over time (table 6.78). Confidence intervals shown in table 6.79 for each time point indicate that although levels of depression change over time and this is significant in the intervention group at T3, there is considerable overlap in estimated mean scores within and between intervention and control samples at all other time points.

Table 6.78 Tests of between-subjects effects for depression in the autologous group

**Tests of Between-Subjects Effects**

Measure: MEASURE\_1  
Transformed Variable: Average

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	2951.709	1	2951.709	92.359	.000
Allocation	77.263	1	77.263	2.418	.134
Error	735.057	23	31.959		

Table 6.79 Confidence intervals for depression in the autologous group

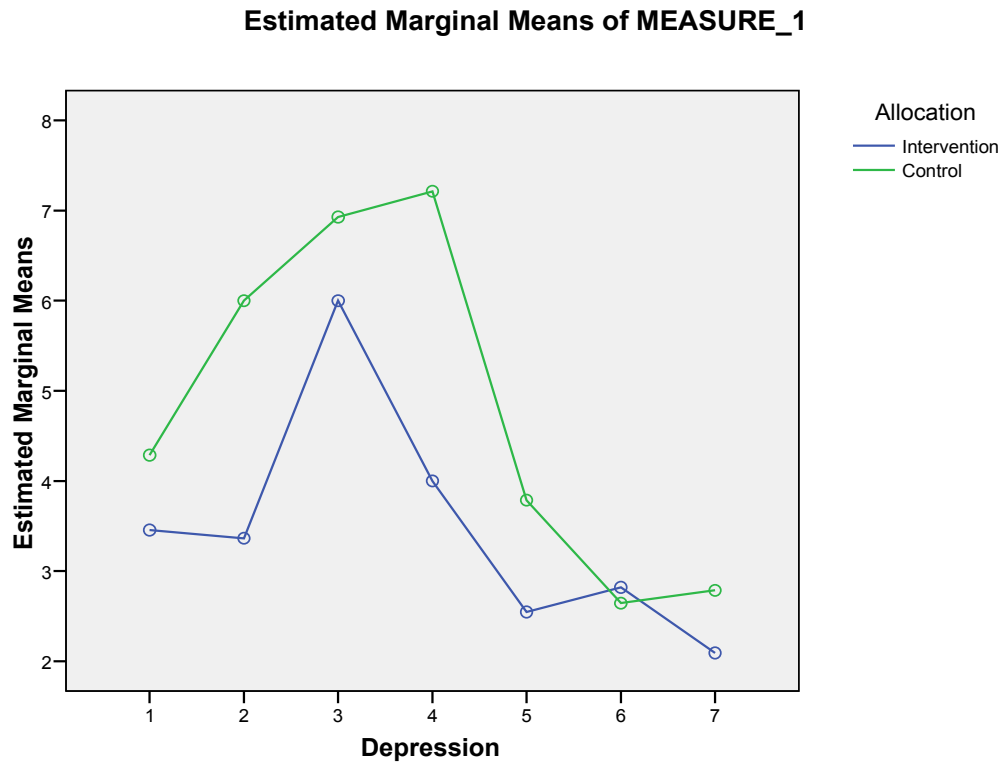
**Allocation \* Depression**

Measure: MEASURE\_1

Allocation	Depression	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
Intervention	1	3.455	.764	1.875	5.035
	2	3.364	.849	1.606	5.121
	3	6.000	1.140	3.641	8.359
	4	4.000	1.429	1.045	6.955
	5	2.545	.703	1.091	4.000
	6	2.818	.926	.903	4.733
	7	2.091	.587	.876	3.306
Control	1	4.286	.677	2.885	5.686
	2	6.000	.753	4.442	7.558
	3	6.929	1.011	4.838	9.019
	4	7.214	1.266	4.595	9.834
	5	3.786	.623	2.496	5.075
	6	2.643	.821	.945	4.340
	7	2.786	.521	1.709	3.863

Figure 6.18 shows the estimated marginal means for levels of depression over the seven time points for the intervention and control samples in the autologous group. There is a downward trend in levels of depression over time with the intervention sample having slightly lower scores than the control. The difference between the intervention and control samples is greatest at T2 and T4 with the control group showing a higher score of between 2 – 3 points.

Figure 6.18 Estimated marginal means for depression in the autologous group over 7 time points



### 6.6.4.3 Distress

Mauchly's test of Sphericity is not significant ( $p=.641$ ) for Distress in the autologous group (table 6.80). This means that this test will be relevant when considering within subject effects.

Table 6.80 Mauchly's Test of Sphericity for distress in the autologous group

Measure: MEASURE_1							
Within Subjects Effect	Mauchly's W	Approx. Chi-Square	df	Sig.	Epsilon <sup>a</sup>		
					Greenhouse-Geisser	Huynh-Feldt	Lower-bound
Distress	.378	17.287	20	.641	.813	1.000	.167

Tests the null hypothesis that the error covariance matrix of the orthonormalized transformed dependent variables is proportional to an identity matrix.

a. May be used to adjust the degrees of freedom for the averaged tests of significance. Corrected tests are displayed in the Tests of Within-Subjects Effects table.

b.  
Design: Intercept+Allocation  
Within Subjects Design: Distress

The test of ‘within-subjects effects’ and the row ‘Distress’ responds to the null hypothesis that levels of distress are constant over time. In this instance the Mauchly’s Test of Sphericity is significant ( $p=.000$ ), this indicates that the null hypothesis is rejected and levels of distress change over time (table 6.81). In the same table, the row ‘Distress\*Allocation’ responds to the hypothesis that intervention and control samples do not mix over time. The sphericity-assumed test is not statistically significant ( $p=.550$ ), therefore, the hypothesis is accepted, intervention and control samples do not exhibit significantly different trends in relation to levels of distress over time (table 6.81).

Table 6.81 Tests of within-subjects effects for distress in the autologous group

**Tests of Within-Subjects Effects**

Measure: MEASURE\_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig.
Distress	Sphericity Assumed	279.065	6	46.511	9.510	.000
	Greenhouse-Geisser	279.065	4.880	57.190	9.510	.000
	Huynh-Feldt	279.065	6.000	46.511	9.510	.000
	Lower-bound	279.065	1.000	279.065	9.510	.006
Distress * Allocation	Sphericity Assumed	24.312	6	4.052	.828	.550
	Greenhouse-Geisser	24.312	4.880	4.982	.828	.530
	Huynh-Feldt	24.312	6.000	4.052	.828	.550
	Lower-bound	24.312	1.000	24.312	.828	.374
Error(Distress)	Sphericity Assumed	586.909	120	4.891		
	Greenhouse-Geisser	586.909	97.592	6.014		
	Huynh-Feldt	586.909	120.000	4.891		
	Lower-bound	586.909	20.000	29.345		

In the table ‘Tests of Between-Subjects Effects’ the row ‘Allocation’ responds to the hypothesis that the intervention and control samples are similar over time. The test is not statistically significant ( $p=.613$ ), therefore, the hypothesis is accepted that the mean score for distress in the intervention and control autologous groups is not significantly different over time (table 6.82). Confidence intervals shown in table 6.83 for each time point indicate that although levels of distress change over time, there is considerable overlap in estimated mean scores for the intervention and control samples.

Table 6.82 Tests of between-subjects effects for distress in the autologous group

**Tests of Between-Subjects Effects**

Measure: MEASURE\_1  
Transformed Variable: Average

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	2229.844	1	2229.844	226.067	.000
Allocation	2.597	1	2.597	.263	.613
Error	197.273	20	9.864		

Table 6.83 Confidence intervals for distress in the autologous group

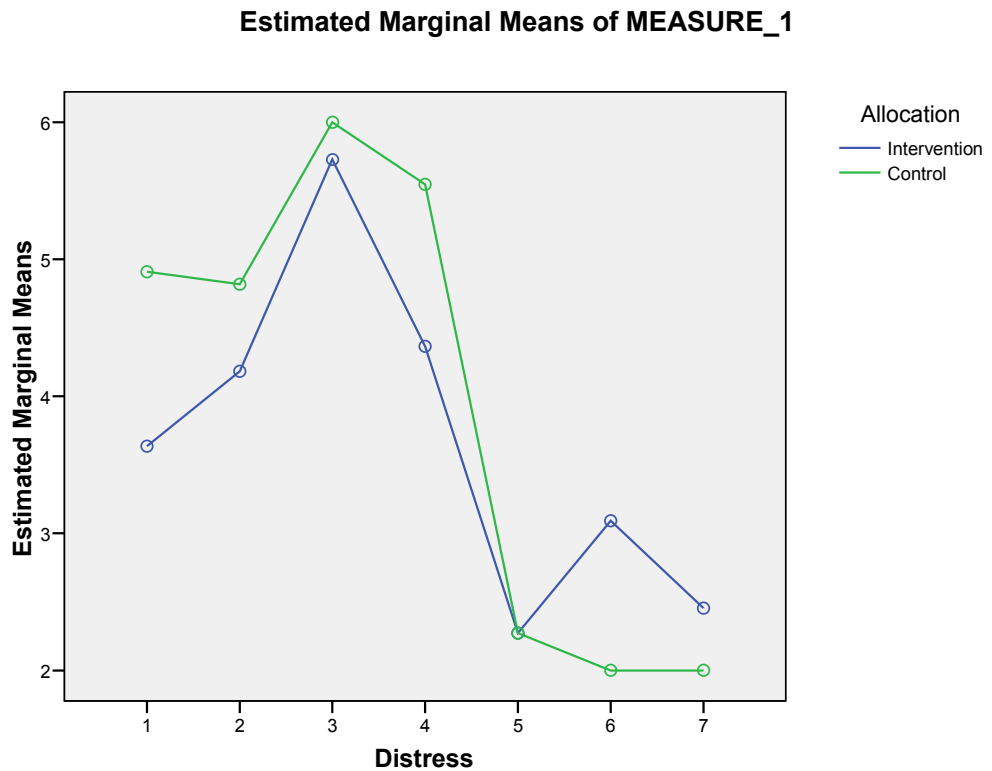
**Allocation \* Distress**

Measure: MEASURE\_1

Allocation	Distress	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
Intervention	1	3.636	.686	2.206	5.067
	2	4.182	.761	2.595	5.768
	3	5.727	.720	4.224	7.230
	4	4.364	.903	2.481	6.247
	5	2.273	.589	1.044	3.502
	6	3.091	.704	1.623	4.559
	7	2.455	.583	1.239	3.670
Control	1	4.909	.686	3.479	6.340
	2	4.818	.761	3.232	6.405
	3	6.000	.720	4.497	7.503
	4	5.545	.903	3.662	7.428
	5	2.273	.589	1.044	3.502
	6	2.000	.704	.532	3.468
	7	2.000	.583	.784	3.216

Figure 6.19 shows the estimated marginal means for levels of distress over the seven time points for the intervention and control samples. Both samples show a downward trend in levels of distress over time. The difference between scores at each data collection point is minimal with highest scores for both samples at T3 and T4.

Figure 6.19 Estimated marginal means for distress in the autologous group over 7 time points



6.6.5 Results of repeated measures ANOVA for the Allogeneic Group

6.6.5.1 Anxiety

Mauchly’s test of Sphericity is not significant ( $p=.123$ ) for Anxiety in the allogeneic group (table 6.84). This means that this test will be relevant when considering within subject effects.

Table 6.84 Mauchley’s Test of Sphericity for anxiety in the allogeneic group

Measure: MEASURE_1								
Within Subjects Effect	Mauchly's W	Approx. Chi-Square	df	Sig.	Epsilon <sup>a</sup>			
					Greenhouse e-Geisser	Huynh-Feldt	Lower-bound	
Anxiety	.420	27.531	20	.123	.813	.993	.167	

Tests the null hypothesis that the error covariance matrix of the orthonormalized transformed dependent variables is proportional to an identity matrix.

a. May be used to adjust the degrees of freedom for the averaged tests of significance. Corrected tests are displayed in the Tests of Within-Subjects Effects table.

b. Design: Intercept+Allocation  
Within Subjects Design: Anxiety



The test of ‘within-subjects effects’ and the row ‘Anxiety’ responds to the null hypothesis that levels of distress are constant over time. In this instance the Mauchly’s Test of Sphericity is significant ( $p=.001$ ), this indicates that the null hypothesis is rejected and levels of distress change over time (table 6.85). In the same table, the row ‘Anxiety\*Allocation’ responds to the hypothesis that intervention and control samples do not mix over time. The sphericity-assumed test is not statistically significant ( $p=.109$ ), therefore, the hypothesis is accepted, intervention and control samples do not exhibit significantly different trends in relation to levels of anxiety over time (table 6.85).

Table 6.85 Tests of within-subjects effects for anxiety in the allogeneic group

**Tests of Within-Subjects Effects**

Measure: MEASURE\_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig.
Anxiety	Sphericity Assumed	123.925	6	20.654	3.876	.001
	Greenhouse-Geisser	123.925	4.878	25.407	3.876	.003
	Huynh-Feldt	123.925	5.961	20.790	3.876	.001
	Lower-bound	123.925	1.000	123.925	3.876	.057
Anxiety * Allocation	Sphericity Assumed	56.243	6	9.374	1.759	.109
	Greenhouse-Geisser	56.243	4.878	11.531	1.759	.126
	Huynh-Feldt	56.243	5.961	9.435	1.759	.110
	Lower-bound	56.243	1.000	56.243	1.759	.194
Error(Anxiety)	Sphericity Assumed	1087.115	204	5.329		
	Greenhouse-Geisser	1087.115	165.839	6.555		
	Huynh-Feldt	1087.115	202.669	5.364		
	Lower-bound	1087.115	34.000	31.974		

In the table ‘Tests of Between-Subjects Effects’ the row ‘Allocation’ responds to the hypothesis that the intervention and control samples are similar over time. The test is not statistically significant ( $p=.706$ ), therefore, the hypothesis is accepted that the mean score for anxiety in the intervention and control allogeneic groups is not significantly different over time (table 6.86). Confidence intervals shown in table 6.87 for each time point indicate that although levels of anxiety change over time, there is considerable overlap in estimated mean scores for the intervention and control samples.

Table 6.86 Tests of between-subjects effects for anxiety in the allogeneic group

**Tests of Between-Subjects Effects**

Measure: MEASURE\_1  
Transformed Variable: Average

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	6443.825	1	6443.825	141.189	.000
Allocation	6.619	1	6.619	.145	.706
Error	1551.746	34	45.640		

Table 6.87 Confidence intervals for anxiety in the allogeneic group

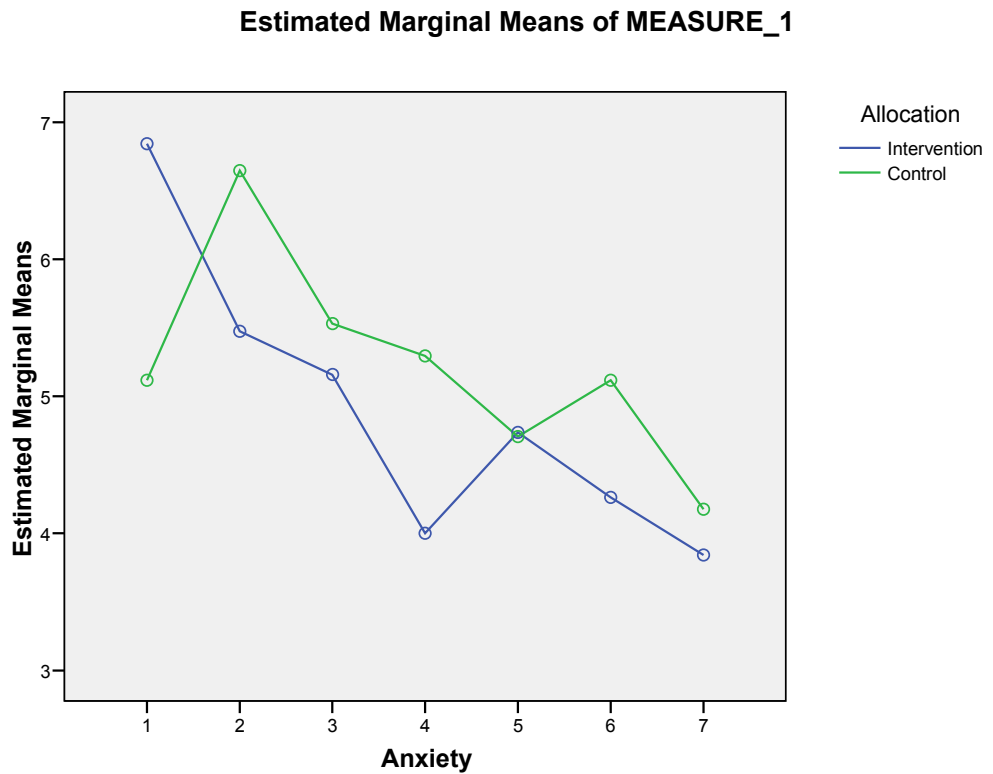
**Allocation \* Anxiety**

Measure: MEASURE\_1

Allocation	Anxiety	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
Intervention	1	6.842	.822	5.172	8.512
	2	5.474	.803	3.842	7.106
	3	5.158	.782	3.569	6.747
	4	4.000	.744	2.488	5.512
	5	4.737	.813	3.084	6.389
	6	4.263	.735	2.768	5.758
	7	3.842	.631	2.560	5.124
Control	1	5.118	.869	3.352	6.883
	2	6.647	.849	4.922	8.372
	3	5.529	.826	3.850	7.209
	4	5.294	.786	3.696	6.892
	5	4.706	.860	2.959	6.453
	6	5.118	.778	3.537	6.698
	7	4.176	.667	2.821	5.532

Figure 6.20 shows the estimated marginal means for levels of anxiety over the seven time points for the intervention and control group. From T2 there is a downward trend in levels of distress over time in both samples. Although the intervention sample report slightly lower scores for level of anxiety, the difference is consistently less than two points over time.

Figure 6.20 Estimated marginal means for anxiety in the allogeneic group over 7 time points



### 6.6.5.2 Depression

Mauchly's test of Sphericity is significant ( $p=.001$ ) for depression (table 6.88). This means that this test will be disregarded when considering within subject effects.

Table 6.88 Mauchly's Test of Sphericity for depression in the allogeneic group

**Mauchly's Test of Sphericity<sup>b</sup>**

Measure: MEASURE\_1

Within Subjects Effect	Mauchly's W	Approx. Chi-Square	df	Sig.	Epsilon <sup>a</sup>		
					Greenhouse-Geisser	Huynh-Feldt	Lower-bound
Depression	.240	45.328	20	.001	.706	.843	.167

Tests the null hypothesis that the error covariance matrix of the orthonormalized transformed dependent variables is proportional to an identity matrix.

a. May be used to adjust the degrees of freedom for the averaged tests of significance. Corrected tests are displayed in the Tests of Within-Subjects Effects table.

b.  
Design: Intercept+Allocation  
Within Subjects Design: Depression

The test of ‘within-subjects effects’ and the row ‘Depression’ responds to the null hypothesis that depression is constant over time. In this instance as Mauchly’s Sphericity test is not appropriate, therefore, the Greenhouse-Geisser test will be used. This test is significant ( $p=0.000$ ) which indicates that the null hypothesis is rejected and levels of depression change over time (table 6.89). In the same table, the row ‘Depression\*Allocation’ responds to the hypothesis that intervention and control samples do not mix over time. The Greenhouse-Geisser test is not statistically significant ( $p=.663$ ), therefore, the hypothesis is accepted, intervention and control samples in the allogeneic group do not exhibit significantly different trends in relation to levels of depression over time (table 6.89).

Table 6.89 Tests of within-subjects effects for depression in the allogeneic group

**Tests of Within-Subjects Effects**

Measure: MEASURE\_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig.
Depression	Sphericity Assumed	313.671	6	52.279	6.542	.000
	Greenhouse-Geisser	313.671	4.236	74.041	6.542	.000
	Huynh-Feldt	313.671	5.057	62.028	6.542	.000
	Lower-bound	313.671	1.000	313.671	6.542	.015
Depression * Allocation	Sphericity Assumed	29.402	6	4.900	.613	.720
	Greenhouse-Geisser	29.402	4.236	6.940	.613	.663
	Huynh-Feldt	29.402	5.057	5.814	.613	.692
	Lower-bound	29.402	1.000	29.402	.613	.439
Error(Depression)	Sphericity Assumed	1630.170	204	7.991		
	Greenhouse-Geisser	1630.170	144.040	11.317		
	Huynh-Feldt	1630.170	171.937	9.481		
	Lower-bound	1630.170	34.000	47.946		

In the table ‘Tests of Between-Subjects Effects’ the row ‘Allocation’ responds to the hypothesis that the intervention and control samples are similar over time. The test is not statistically significant ( $p=.136$ ), therefore, the hypothesis is accepted that the mean score for depression in the intervention and control samples in the allogeneic groups is not significantly different over time (table 6.90). Confidence intervals shown in table 6.91 for each time point indicate that although levels of depression change over time and this is significant in the

intervention group at T3, there is considerable overlap in estimated mean scores within and between intervention and control samples at all other time points.

Table 6.90 Tests of between-subjects effects for depression in the allogeneic group

**Tests of Between-Subjects Effects**

Measure: MEASURE\_1  
Transformed Variable: Average

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	3770.644	1	3770.644	128.905	.000
Allocation	68.136	1	68.136	2.329	.136
Error	994.542	34	29.251		

Table 6.91 Confidence intervals for depression in the allogeneic group

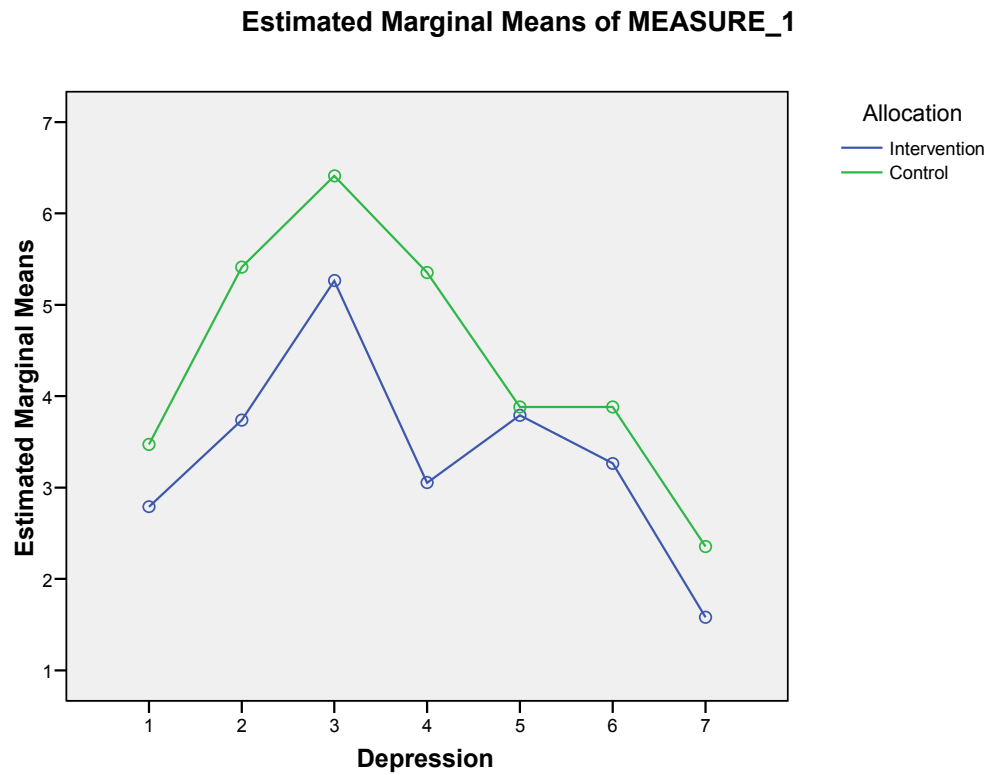
**Allocation \* Depression**

Measure: MEASURE\_1

Allocation	Depression	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
Intervention	1	2.789	.533	1.707	3.872
	2	3.737	1.015	1.674	5.800
	3	5.263	1.003	3.225	7.301
	4	3.053	.796	1.436	4.669
	5	3.789	.662	2.445	5.134
	6	3.263	.660	1.922	4.605
	7	1.579	.486	.591	2.566
Control	1	3.471	.563	2.326	4.615
	2	5.412	1.073	3.231	7.593
	3	6.412	1.060	4.257	8.567
	4	5.353	.841	3.644	7.062
	5	3.882	.700	2.461	5.304
	6	3.882	.698	2.464	5.300
	7	2.353	.514	1.309	3.397

Figure 6.21 shows the estimated marginal means for levels of depression over the seven time points for the intervention and control samples in the allogeneic group. This illustrates a downward trend in level of depression in both samples from T3 onwards with the intervention sample reporting slightly lower scores over time.

Figure 6.21 Estimated marginal means for depression in the allogeneic group over 7 time points



### 6.6.5.3 Distress

Mauchly's test of Sphericity is not significant ( $p=.871$ ) for distress in the allogeneic group (table 6.92). This means that this test will be relevant when considering within subject effects.

Table 6.92 Mauchly's Test of Sphericity for distress in the allogeneic group

**Mauchly's Test of Sphericity<sup>b</sup>**

Measure: MEASURE\_1

Within Subjects Effect	Mauchly's W	Approx. Chi-Square	df	Sig.	Epsilon <sup>a</sup>		
					Greenhouse e-Geisser	Huynh-Feldt	Lower-bound
Distress	.652	13.167	20	.871	.885	1.000	.167

Tests the null hypothesis that the error covariance matrix of the orthonormalized transformed dependent variables is proportional to an identity matrix.

a. May be used to adjust the degrees of freedom for the averaged tests of significance. Corrected tests are displayed in the Tests of Within-Subjects Effects table.

b.  
Design: Intercept+Allocation  
Within Subjects Design: Distress

The test of ‘within-subjects effects’ and the row ‘Distress’ responds to the null hypothesis that levels of distress are constant over time. In this instance the Mauchly’s Test of Sphericity is significant ( $p=.000$ ), this indicates that the null hypothesis is rejected and levels of distress change over time (table 6.93). In the same table, the row ‘Distress\*Allocation’ responds to the hypothesis that intervention and control samples do not mix over time. The sphericity-assumed test is not statistically significant ( $p=.319$ ), therefore, the hypothesis is accepted, intervention and control samples do not exhibit significantly different trends in relation to levels of distress over time (table 6.93).

Table 6.93 Tests of within-subjects effects for distress in the allogeneic group

**Tests of Within-Subjects Effects**

Measure: MEASURE\_1

Source		Type III Sum of Squares	df	Mean Square	F	Sig.
Distress	Sphericity Assumed	196.385	6	32.731	7.149	.000
	Greenhouse-Geisser	196.385	5.313	36.964	7.149	.000
	Huynh-Feldt	196.385	6.000	32.731	7.149	.000
	Lower-bound	196.385	1.000	196.385	7.149	.012
Distress * Allocation	Sphericity Assumed	32.401	6	5.400	1.180	.319
	Greenhouse-Geisser	32.401	5.313	6.099	1.180	.321
	Huynh-Feldt	32.401	6.000	5.400	1.180	.319
	Lower-bound	32.401	1.000	32.401	1.180	.285
Error(Distress)	Sphericity Assumed	906.489	198	4.578		
	Greenhouse-Geisser	906.489	175.324	5.170		
	Huynh-Feldt	906.489	198.000	4.578		
	Lower-bound	906.489	33.000	27.469		

In the table ‘Tests of Between-Subjects Effects’ the row ‘Allocation’ responds to the hypothesis that the intervention and control samples are similar over time. The test is not statistically significant ( $p=.796$ ), therefore, the hypothesis is accepted that the mean score for distress in the intervention and control allogeneic groups is not significantly different over time (table 6.94). Confidence intervals shown in table 6.95 for each time point indicate that although levels of distress change over time, there is considerable overlap in estimated mean scores for the intervention and control samples.

Table 6.94 Tests of between-subjects effects for distress in the allogeneic group

**Tests of Between-Subjects Effects**

Measure: MEASURE\_1  
Transformed Variable: Average

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Intercept	3600.609	1	3600.609	260.699	.000
Allocation	.936	1	.936	.068	.796
Error	455.774	33	13.811		

Table 6.95 Confidence intervals for distress in the allogeneic group

**Allocation \* Distress**

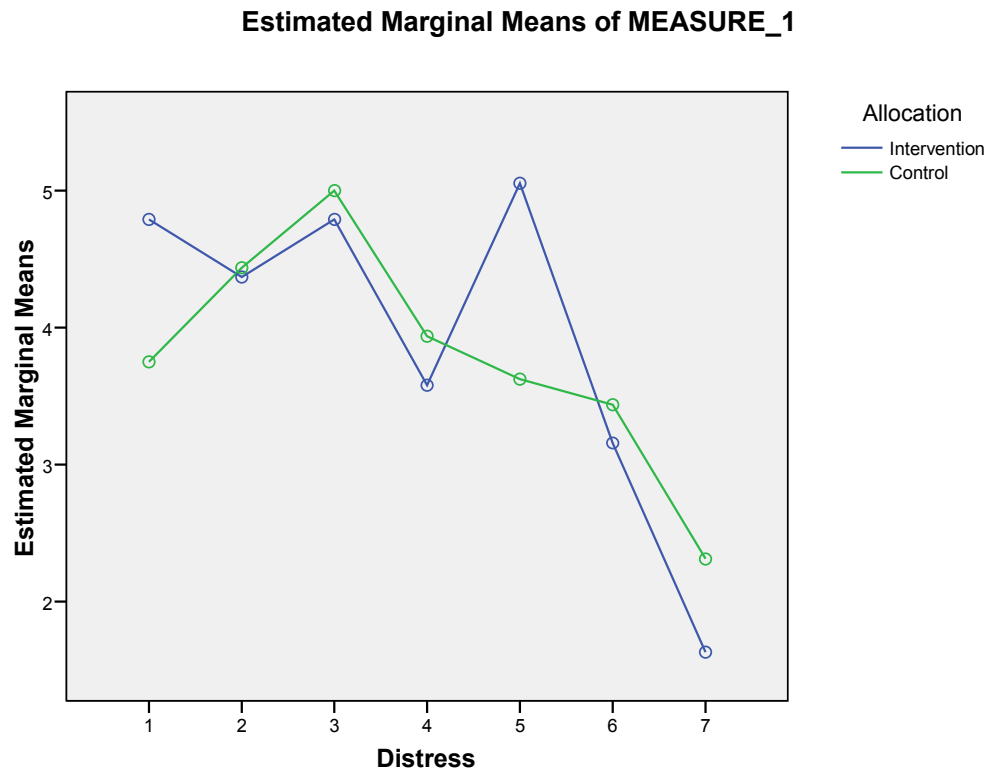
Measure: MEASURE\_1

Allocation	Distress	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
Intervention	1	4.789	.619	3.530	6.049
	2	4.368	.614	3.119	5.618
	3	4.789	.597	3.576	6.003
	4	3.579	.633	2.290	4.868
	5	5.053	.457	4.124	5.982
	6	3.158	.467	2.209	4.107
	7	1.632	.479	.657	2.606
Control	1	3.750	.674	2.378	5.122
	2	4.437	.669	3.076	5.799
	3	5.000	.650	3.677	6.323
	4	3.938	.690	2.533	5.342
	5	3.625	.498	2.613	4.637
	6	3.437	.508	2.403	4.472
	7	2.312	.522	1.251	3.374

Figure 6.22 shows the estimated marginal means for levels of distress over the seven time points for the intervention and control group. The highest scores for distress for both samples are reported at T1 and T2 with the intervention sample peaking at T5. The highest difference between the samples is consistently less than 2 points.



Figure 6.22 Estimated marginal means for distress in the allogeneic group over 7 time points



Repeated measures ANOVA by allocation, age and gender did not identify any statistically significant difference in scores between the intervention and control samples of the autologous and allogeneic groups.

### 6.7 Post hoc power calculations

Using the observed values for variability from the samples, post hoc power calculations were applied to the allocation variable. The software package R version 2.5.1 (R Development Core Team 2007) was used for these calculations. In relation to the anxiety scale of the HADS, post hoc calculations reveal a 73.5% power to detect a difference of two points between the intervention and control groups. In this instance, however, the observed difference between was substantially less. Calculations were not conducted for the depression scale of the

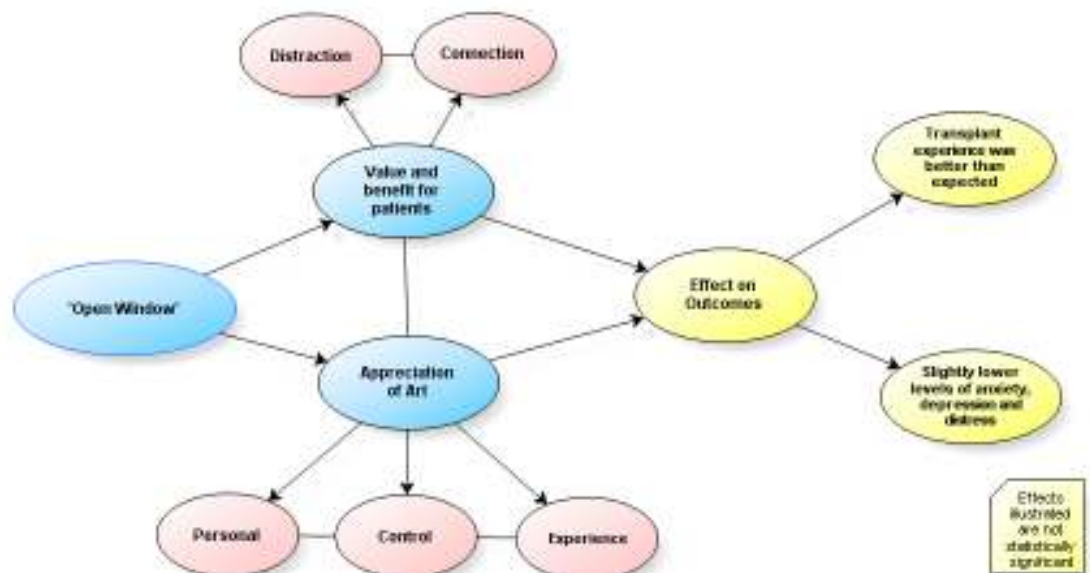
HADS because a statistically significant finding for the depression scale was found, thus a post hoc power analysis is not relevant.

Post hoc calculations for the distress scale revealed an 88% power to detect a difference of two points.

### 6.8 Value, Benefits and Effect of ‘Open window’ for Patients

A large amount of data has been presented in this chapter and in order to clarify what has emerged the NVivo Model tool was used to create a model depicting the value and benefit of ‘Open Window’ for participants in this study and its influence on their overall experience. This model also highlights its potential effect on the psychological outcomes of anxiety, depression and distress (Figure 6.23).

Figure 6.23 Model depicting the value, benefits and effect of ‘Open Window’ for patients undergoing stem cell or bone marrow transplantation in the Denis Burkitt Unit.



## **6.9 Summary**

Results for the expectations questionnaire suggest that participants in the allogeneic group had an experience that was a little or much better than expected when compared with the autologous group. When results are examined between the intervention and control samples in the allogeneic and autologous groups, it is evident that the intervention sample reported having an overall experience that was a little better or much better than expected when compared with the control group. Comparisons between the groups in terms of age, gender and education level did not show significant differences. Qualitative data showed little or no difference in relation to the number of sources for participants' expectations in relation to physical or psychological well-being.

Results for the 'Open Window' survey questionnaire found that overall the participants from both the allogeneic and autologous groups were positive about their experience. The allogeneic groups were more consistently positive in their responses than the autologous groups, which tended to mark the negatively phrased statements more highly. Qualitative data suggests that participants from both groups valued 'Open Window' for its ability to connect them with the outside world and distract them from their illness and situation. They were also able to verbalise their appreciation of art regardless of the acute clinical context and being treated for a life threatening illness. The long term effect of 'Open Window' in increasing participants' interest in art, although minimal, was evident in a small number of participants.

Qualitative data indicate that although many participants reported experiencing stress, it was not a chronic problem and they dealt with it primarily through support from family and friends. Watching TV, reading and prayer were also listed by a small number of participants as being helpful in dealing with stress. Similarly, although many participants reported not having control over their lives, it was not always regarded as a negative issue and others felt that it was

short term. Nearly all participants felt that they would regain control by returning to normal, simple aspects of life such as walking, household chores, and driving. Participants in this study also consistently reported that relationships with their family were very good and in many cases stronger and closer than before they became ill. The majority of participants seemed surprised by the depth of their inner strength and ability to deal with their situation. These data provided a context and possible explanation for the levels of anxiety, depression and distress reported by the participants over time.

Statistical testing shows little or no difference (no more than one point) between the overall HADS-A and HADS-D scores for the allogeneic and autologous groups. Similarly there is little or no difference (no more than one point) in the scores between the groups for the distress thermometer. When the results are illustrated over time, there is a clear downward pattern in the levels of anxiety, depression and distress experienced by the participants over time with it peaking generally from T1 to T4 and declining to moderate to low levels at T7. Repeated measures ANOVA with between-subjects effects shows that although the intervention samples in both groups report slightly lower scores in relation to anxiety, depression and distress, this difference is small (usually no more than 2 – 3 points) and is not statistically significant.

## **6.10 Conclusion**

The results of the statistical analysis of the psychometric tools suggest that at this halfway stage of the study, the null hypothesis is accepted. However, the fact that the intervention samples in the HADS-A, HADS-D, and the DT exhibit a lower score than the control samples at this interim stage of the study suggests a potential psychological effect if the trend continues with a larger sample. The experience of the intervention samples of both groups as being a little better or a lot better than expected implies that ‘Open Window’ may also have a statistically significant effect if this trend continues with a larger sample. The results of the ‘Open Window’ survey indicate that it is perceived positively by the participants,

who prefer moving images and value its ability to connect and distract them from their immediate situation and environment.

Post hoc calculations indicate a 73.5% power for the anxiety scale of the HADS and an 88% power for the DT to detect a difference of two points between the intervention and control samples; however, at this interim stage of the study where recruitment and data collection is just half way through completion, the current results are questionable and may not be used to make definitive statements about any possible effect of 'Open Window'. This interim analysis is useful, though, to indicate that there is no discernable effect, either good or bad, of using 'Open Window' with this patient population. The study may, therefore, with confirmation from the external study monitor, continue to completion, at which stage a full analysis of all results will be conducted.

## **Chapter 7: Discussion of Findings and Recommendations**

### **7.1 Introduction**

This chapter presents a discussion on the findings with reference to relevant literature and the theories that form the conceptual framework (outlined in chapter 3) used to construct the context in which the ‘Open Window’ project and this study took place. The primary aims of this study were to test the null hypothesis and identify differences between the groups in relation to their levels of anxiety, depression and distress over time and in their overall experiences of having a transplant (section 4.3). The research questions and aims of the study will be used to provide a logical, clear structure for the discussion. It is emphasised that, due to the small sample size, points raised and discussion based on the results presented in the previous chapter are tentative and not applicable to the whole stem cell or bone marrow transplant population.

### **7.2 Effect of ‘Open Window’ on participants’ psychological well-being**

The main purpose of this study was to test the null hypothesis, which stated that ‘Open Window’ had no effect on patient’s levels of anxiety, depression, or distress when undergoing a stem cell or bone marrow transplant. The statistical test repeated measures analysis of variance (ANOVA) with between-group factors was applied to anxiety, depression and distress levels, to identify the main effect of ‘Open Window’ on these outcomes over time, for the groups and any interaction effect. The results indicate that levels of anxiety, depression and distress change over time in both the intervention and control groups, and exhibit a downward trend from the highest points from the time of admission at T1 to T4 (7 days after transplant) and T5 (60 days after transplant) where they begin to fall. Whether the scores from the intervention and control samples of the allogeneic and autologous group are tested together or separately similar patterns are evident. It is clear that at the majority of time points the scores for the

intervention samples are lower than the control samples; however the differences are not statistically significant at this interim phase in the study.

In relation to the anxiety scale of the HADS, post hoc calculations reveal a 73.5% power to detect a difference of two points between the intervention and control groups. In this instance, however, the observed difference between the groups was no bigger than 2 points at any time over the six months. Similar calculations for the distress scale revealed an 88% power to detect a difference of two points. Again the difference between the groups over the six months was never more than this. Although differences between the groups were not large, that is, more than two points in the levels of distress, anxiety or depression, small differences were detected, therefore it is feasible to suggest that even with the current small sample size, 'Open Window' demonstrates a positive trend in terms of its psychological effect. Larger numbers in the study may widen these differences and provide a statistically significant result. Due to the small number of participants included in this interim phase of analysis, it is not appropriate at this stage to reject or accept the null hypothesis. Moreover, as no adverse effects have been noted in either group, it is acceptable for the study to continue until the sample size determined *a priori* is reached.

When the results of the expectations questionnaire are examined according to each group, the difference between the intervention and control samples is not statistically significant. However, in contrast to the HADS and DT, when the intervention and control samples from the allogeneic and autologous groups are combined, the results show a marked difference between the groups with almost 66% of the intervention samples and only 32.3% of the control samples from both groups stating that their experience of having a stem cell or bone marrow transplant was better than expected. This difference is statistically significant ( $p=.008$ ). The experience of 'Open Window' may be the reason for these differences with those in the intervention sample appearing to have a more positive experience than those in the control sample (table 6.30).

Interestingly, the results also indicate a statistically significant ( $p=.007$ ) between the genders with males reporting having an experience that was better than expected (table 6.18). This is a little surprising given the literature in relation to men's health in particular, which suggests that men are less expressive and in-tune with their somatic selves than women (Moynihan 1998, Moynihan 2002, Seale 2002). This suggests that females were more likely to have a worse experience than males but it could also reflect women being more likely to verbalise negative issues relating to their care and environment, or emotional and psychological problems, as a means of dealing with them (Moynihan 1998, Moynihan 2002). However, as the qualitative data indicates, men in this study verbalised, equally, the issues in relation to their physical and psychological expectations, therefore, another possible and perhaps more likely reason is the higher number of males in the study than females.

#### 7.2.1 Participants' level of anxiety, depression and distress between groups

The findings of this study present a clear picture of how the levels of anxiety, depression and distress change over a six month period for patients who undergo stem cell or bone marrow transplantation. Although not generally high, the scores reported in this study identify a clear trend in the pattern of levels of anxiety, depression and distress with T1 (admission), T2 (day before transplant, T3 (7 days post transplant) and T4 (before discharge) identifying the highest levels for anxiety in autologous and allogeneic groups; however, although scores are quite low, anxiety remains an issue for participants up to T7. Levels of depression show a similar trend and peak at T3, T4 and T5 (6 weeks post transplant) followed by lower scores at T6 (3 months post transplant) and T7 (6 months post transplant). Levels of distress show a similar trend peaking at T4 for the autologous group and T5 for the allogeneic group. As adverse and intense physical and/or emotional problems seem to be the main cause of higher levels of distress, the higher levels of distress sustained by the allogeneic group can probably be explained by the somewhat longer recovery period required due to



physical symptoms and complications due to graft versus host disease or infection. There is not, however, a large difference in scores or trends over time in levels of anxiety, depression and distress between the allogeneic and autologous groups. Levels of depression and distress show a more obvious downward trend over time than anxiety, which drops no lower than 4 at any time point over the six month continuum. This suggests that even in the recovery phase when life is returning to some normality, participants in this study experienced reasonably low but consistent levels of anxiety. Age, gender or education levels were not a factor in levels of anxiety, depression or distress experienced by participants in this study. It is likely, therefore, that the source of this persistent low-level anxiety is, simply and understandably, the life threatening nature of their illness. Although very few studies have measured levels of anxiety, depression and distress in such a frequent manner over the actual transplant experience and recovery, there is some evidence to support the findings from this study. Patient reported levels of anxiety, depression and distress in studies by Hjermstad et al. (1999), Keogh et al. (1998) and Fife et al. (2000) show similar patterns to this study and also indicate that it is usually between 6-12 months that they return to pre-transplant levels in both groups.

It is possible that, as discussed in chapter 2, the primary factors influencing an individuals' perception of quality of life include culture, philosophy, politics and context as well as psycho-social aspects of their lives (Caplan 1987), and not physical symptoms. The results from this study appear to support this view. The quantitative data illustrates the existence of low to moderate levels of anxiety, depression and distress over time. The qualitative data provide some explanation for this in identifying family and friends as the greatest support in dealing with levels of stress. In contrast to Caplan's (1987) view, Hirai et al. (2008) suggest that being diagnosed with cancer is a very stressful event and is subsequently followed by equally stressful treatments that frequently cause increased feelings of anxiety, depression and distress. Although this is supported by this study with qualitative data indicating that 48 participants experienced stress at some

stage during their treatment and recovery, 20 participants said they did not. Appendix 19f shows that participants from both autologous and allogeneic groups referred to their experiences of stress frequently, with 88 references from those who experienced stress and 55 from those who did not. However, the stress experienced seemed to be acute rather than chronic and was primarily related to unexpected side effects of medication or communication issues and did not increase participants' levels of anxiety, depression or distress significantly.

Studies by Ho et al. (2002) and Parker et al. (2003) suggest that assessing patients' level of family or social support is perhaps the most accurate way of identifying patients at risk for anxiety, depression or distress during treatment for cancer. However, another possible explanation for the low to moderate levels of anxiety, depression and distress lies in Van't Spijker et al's (1997) meta-analytical review of studies on the psychological sequelae of cancer diagnosis. This review included 58 studies conducted between 1980 and 1994 and concluded that the amount of psychological and mental health problems in patients with cancer does not differ from the normal population. Although this evidence is somewhat dated, more recent studies also report normal to moderate levels of anxiety, distress and depression in patients undergoing stem cell or bone marrow transplantation for the treatment of haematological cancer (Trask et al. 2002, Patrick-Miller et al. 2004, Prieto et al. 2005). Experiencing a life threatening illness may of course influence an individuals' perception of their quality of life and this may be as a result of the consistent presence of a raised level of anxiety over time. However, it appears that the ability, or even the prospect of having the ability, to live a 'normal' life with family and friends is sufficient to maintain a perception of a reasonable quality of life for participants in this study. This is evident in the relatively low scores for anxiety, depression and distress over time and is supported by the qualitative data, which identify returning to normal life and family as being the main focus of participants' recovery and future plans.

Osowiecki and Compas (1998) conducted a study that examined how control, beliefs and coping in adult cancer patients influenced psychological adjustment to cancer diagnosis and treatment. Semi-structured interviews, the Impact of Events Scale and the Beck Depression Inventory were used with 83 adult cancer patients to collect data on coping with the stress of having cancer diagnosis and treatment. Correlational and regression analyses indicated that the use of problem-focused coping was related to less emotional distress. This, in conjunction with high perceptions of personal control, was associated with lower symptoms of anxiety and depression. Qualitative aspects of this study showed that this type of coping involved asking questions and seeking information about their disease, readily taking advice and complying with treatment recommendations, and actively solving or dealing with stressors caused by physical symptoms such as pain or nausea, that occurred as a result of the cancer and treatment. Problem-focused coping is defined as a coping style engaged by some people in order to manage or alter the person-environment relationship that is the source of stress (Folkman and Lazarus 1980, Folkman et al. 1986). They also identify an alternative coping style as emotion-focused which attempts to regulate stressful emotions.

In 1999, Osowiecki and Compas conducted a similar prospective study that examined coping, perceived control and psychological adaptation to breast cancer. They used the same semi-structured interview technique, the Symptom Checklist-90-Revised (SCL-90) and the Coping Strategies Inventory to collect data from 70 women. This study also concluded that problem-focused coping in conjunction with perceived control was a significant predictor of lower levels of anxiety and depression. A longitudinal study of adaptation to the stress of bone marrow transplantation by Fife et al. (2000) using the Mastery Scale also concluded that the greater the individual's sense of control over his/her life, the less emotional distress was experienced. Frick et al. (2004) conducted a study with 126 patients exploring their health beliefs and coping styles prior to autologous stem cell transplantation. Participants completed the questionnaire of

health related control expectancies, the questionnaire of personal illness causes and the Freiburg questionnaire of coping with illness. The highest scores were found for 'active coping' which was associated with patients perceiving that others, including doctors, nurses and close family are relevant and important for managing their disease. The 'Open Window' study supports the findings of these studies from both a quantitative and qualitative perspective. Two thirds of the participants in this study reported that they had either complete control or some control over their lives (figure 6.11). Only one third felt that they had no control and while this produced negative feelings in some participants many also commented that this was not a problem because they trusted the health care staff and understood that they needed to go through this in order to get better (section 6.4.4). The results of this study indicate that although commonly associated with a diagnosis and treatment of cancer, stress and control issues can be positively addressed by patients who have adjusted well psychologically to their illness. This is reflected in the low to moderate levels of anxiety, depression and distress over time (section 6.4.4.2).

These results have implications for the approach nurses and doctors use when assessing patients' psychological adjustment to cancer diagnosis or treatment as the basis for providing appropriate psychological and physical care that is individualised. It appears from this study, and those referred to previously, that patients with cancer adjust quite well psychologically with the experience of having cancer by using strategies that increase their perception of control. However, studies by Martensson et al. (2008) and Fitzsimmons et al. (1999) report that health care staff tend to overestimate patient's emotional distress and underestimate patients' coping resources and quality of life. Lampic and Sjoden (2000), in their review of 22 studies that explored patient and staff perceptions of cancer patients' psychological concerns and needs support this view and suggest that this can have a negative impact on patient's perception of how they are coping given that health care staff constitute a substantial part of patients' social environment throughout treatment and recovery. Sprangers and Sneeuw (2000)

are somewhat critical of Lampic and Sjoden's (2000) conclusion on the basis of quite pervasive methodological weaknesses in the studies and also perhaps more importantly they identify the subjective nature of distress and anxiety as the most likely source for discrepancies between staff and patients. They suggest that this precludes full awareness of the nature of these psychological concerns for patients by health care staff. Martensson et al. (2008), Lampic et al. (1996) and Wright (1983) concur with this and provide further explanation by describing how health care staff have expectations of cancer patients' psychological state based on their own feelings about how they themselves might react to a diagnosis of cancer. According to Ubel et al. (2003), healthy people tend to both overestimate problems associated with disease/disability and underestimate their own ability to cope with them if diagnosed. This may explain why participants in this study expressed such surprise at how well they responded psychologically to cancer diagnosis and treatment. It seems that with family support and coping strategies that maintain perceived levels of control, the transition from a healthy person to one with a life threatening illness can be achieved with relatively low levels of psychological morbidity.

Understanding and being aware of one's own feelings about cancer, its treatment, and associated mortality seem to be an integral requirement to caring for cancer patients in an individualised way. Otherwise communication strategies that are shown to reduce levels of anxiety and depression such as using the word 'cancer', discussing life expectancy and how cancer might affect other aspects of life could be used effectively in helping patients with cancer (Schofield et al. 2003). Although not a common problem in this study, narratives recounting experiences of negative communication support this point and demonstrate how it can make patients feel more anxious or unsure of themselves. Thornton (2002) suggests that it is important for health care professionals to understand the positive approach that many patients use in adjusting and living with cancer diagnosis and treatment. Taking time to understand the patients' belief system

and the process and value of this type of adjustment may prevent insensitive communication and the expectation of unrealistic outcomes on both sides.

The literature and both quantitative and qualitative findings from this study seem to support Brennan's (2001) Social Cognitive Transition (SCT) Model of Adjustment discussed in chapter 2. It is worth revisiting the key components of this model in explaining findings from this study. The SCT model of adjustment comprises 4 key components, which include 'life trajectory', 'beliefs about the self: control and self-worth', 'nature of attachments', and 'spiritual/existential'. In terms of Brennan's (2001) Social-Cognitive Transition (SCT) model of adjustment, the implications are that participants tend to adjust to having a life threatening illness quite successfully. Qualitative data from this study suggest that most participants perceived that they had at least some control and even for those that said they did not, it did not generally evoke negative feelings. They also dealt with stress through the use of strong family support, friends, and prayer. This may go some way towards explaining the relatively low scores and trends in levels of anxiety, depression and distress. The problem perhaps only arises when they perceive that they have survived and reflect on how this affects their 'life trajectory'; however, commenting on this is beyond the capabilities and remit of this study.

According to Brennan (2001), coping theory does not help explain the different ways in which people deal with cancer diagnosis and treatment. He developed the SCT model of adjustment that presents a dynamic fluid process consisting of both positive and negative experiences for patients. It is based on the belief that humans are self-regulating, exist in a particular social and cultural context, and therefore adapt to their situation using a unique frame of reference. As the literature and Brennan's model suggest, the success of adjustment is greatly influenced by the individual's perceived level of social support and control, which, if strong, maintains their sense of self and self-esteem. According to the SCT model of adjustment, an important part of positive psychological adjustment

is identifying and modifying long and short term goals, having a sense of control and redefining views of human existence. An unexpected and surprising finding that emerged from the qualitative part of this study was the theme 'Self and Others'. This very important theme provides detailed subjective explanation of the process described by Brennan (2001) in the SCT model of adjustment. This theme showed how participants in this study emerged as psychologically robust throughout their experience of transplantation, seemed proud of how they dealt with it and recognised and valued the support of family and friends. Qualitative data showed how the experience of having cancer and undergoing treatment seemed to result in stronger personal relationships for the participants. It also demonstrated how participants identified and modified short term goals, in particular by focusing on returning to normal everyday activities such as driving, walking and household chores. They redefined aspects of their existence by prioritising personal issues such as time with family and friends above other pre-cancer diagnosis activities. They also felt that they were no longer concerned or irritated about 'silly' things in life and generally perceived that they were more relaxed. Whitford et al. (2008) relate this process to patients being compelled to find congruence between the situational and global meaning in their situation and because this relates to aspects of their lives such as redefining and focusing on specific goals and control issues, they also suggest that this is a similar concept and process to adjustment or coping style. The emergence of this unexpected theme 'Self and Others' from the qualitative data in this study supports the use of mixed methods in clinical trials because it helped to explain the low scores over time for levels of anxiety, depression and distress in patients undergoing treatment for a life threatening illness. This type of information can help health care professionals to understand the most important issues for patients in psychological adjustment to life threatening or even chronic illness, therefore they can empathise more effectively and in doing so, provide care that is individualised and patient-centered.

### 7.2.3 Anxiety, Depression and Distress in the Autologous and Allogeneic Groups

As discussed in chapter 3, the HADS and DT are psychometric tools commonly used to screen cancer patients for increased levels of anxiety, depression or distress in order to ascertain the potential or actual need for psychological or psychiatric intervention (Roth et al. 1998, Trask et al. 2002, Akizuki et al. 2003, Hoffman et al. 2004, Akizuki et al. 2005, Lee et al. 2005, Gessler et al. 2008, Zwahlen et al. 2008). In this study, however, they were used in clinical trial conditions to measure the psychological effect of ‘Open Window’ over time, on patients undergoing bone marrow or stem cell transplantation for the treatment of hematological malignancies. It is worth noting that neither the autologous nor the allogeneic group exceeded the cut-off score of  $\geq 4$  for levels for distress as suggested by Jacobsen et al. (2005) and Patrick-Miller et al. (2004) for optimal sensitivity and specificity. The mean scores over time for both groups were equal at 4. For the HADS, a cut-off score of 8 or above is recommended by Zigmond and Snaith (1983) as an indication of the presence of significant mood disorder. In this study the mean score for anxiety and depression in both groups did not exceed 7, which is below the cut-off score indicating the need for intervention. According to Snaith (2003) a score of 0-7 can be regarded as being in the normal range with a score of 8-10 suggesting the presence of low levels of anxiety or depression. A 3-year prospective inpatient study by Prieto et al. (2005), which examined patient-rated emotional and physical functioning among hematologic cancer patients during hospitalisation for stem-cell transplantation, also reported no significant differences in anxiety and depression scores between the autologous and allogeneic transplant groups.

Interestingly, this suggests that although stratified sampling and randomisation were used in this study due to perceived differences in psychological and physical morbidity, in contrast to Neitzert’s view (1998), this may not be as big an influence as initially thought. A review of the literature identifies 42 studies in the last 10 years that explored quality of life issues in relation to autologous and allogeneic transplantation collectively. Sixteen studies addressed quality of



life issues within the autologous population only and 10 within the allogeneic population. One of the main reasons that researchers have not used stratified sampling may be the significant amount of time required to recruit sufficient numbers from either population to a study, which of course adds cost also. Another reason is that many researchers do not perceive that there are substantial psychological differences, in spite of the specific risks and benefits associated with each type of transplant. There is some evidence from this study which, although it should be viewed tentatively at this stage, supports this view.

### **7.3 Influence of ‘Open Window’ on participants’ experience**

#### **7.3.1 Introduction**

The influence of ‘Open Window’ on participants’ overall experience of having a transplant was assessed using all the questionnaires and interviews. As already discussed in the previous section, at this interim phase of the study, ‘Open Window’ seems to have a positive influence on patient reported levels of anxiety, depression and distress; however, this not statistically significant. This could be due to the small sample size or the overall low levels of anxiety, depression, and distress experienced by the participants generally.

#### **7.3.2 How patients used ‘Open Window’**

The ‘Open Window’ survey questionnaire indicated that most patients had a positive experience of ‘Open Window’ and were not intimidated by its technical characteristics, with all reporting that they were able to use the technology. Fifty percent or more of both groups watched ‘Open Window’ three or four days per week but a higher percentage of those in the allogeneic group turned it on five or six days per week and an equally low percentage in both groups looked at it every day. There was generally no set pattern as to what time of day it was turned on and it was most commonly left on for up to an hour. Participants in this study often described being “too sick to be interested in anything”. This included TV, texting or phoning friends/family, reading and ‘Open Window’.

There was also a period in which participants were acutely unwell and experiencing severe side effects of treatment and medication. It was not expected that they would be particularly interested in 'Open Window' at this time, although where relevant, images of their children tended to be viewed on a more regular basis. Although not available at the time of writing up these results, it would be helpful to view electronic data of how 'Open Window' was used by the participants; this may identify a trend that illustrates and correlates with what participants say about being too sick to do anything at particular stages in their treatment. This information will be available at a later date.

### 7.3.3 'Open Window' as a distraction

As discussed earlier in this chapter (section 7.2), results from the expectations questionnaire indicate that 'Open Window' has had a statistically significant effect on participants experience of having a stem cell or bone marrow transplant with those who experienced it from both groups reporting a better than expected experience than those who did not ( $p=.008$ ). The source of this effect can be found in participants' comments on their perceptions of 'Open Window' and the feelings it generated. Qualitative data suggest that patients valued 'Open Window' because of its ability to provide a distraction from their immediate environment and situation, something different to look at or talk about with staff. The distraction seemed to give participants an experience outside their illness and treatment. In chapter 2, I referred to how Benson (1993) proposed that to regard art as merely a distraction is an attempt to control the viewer and while some level of absorption may occur it is not patient led and does not result in new experiences of situations for the patient. The findings from this study would not concur with this view of art as participants appeared to welcome and value the distraction. Perhaps it is feasible to suggest that art can be a distraction in a non-controlling way if the viewer says it is and not the artist or provider.

#### 7.3.4 'Open Window' as a Connection with the Outside World

For some participants 'Open Window' also provided a sense of connection with the outside world. This sense of connection seemed to be based on individual meaning that participants saw in the 'Open Window' images. It allowed them to relax and reflect on their lives. This related not just to family images but also familiar places. They saw meaning because they could imagine being in the place they saw on the image as opposed to being confined in the Denis Burkitt Unit. They also saw meaning in familiar images because they were a visual representation of their goal of returning to 'normal' life. The strength of the sense of connection is demonstrated by an unexpected request by some participants (n=10) to have a copy of the family/local images to take home when they were being discharged. Clearly participants recognised these images as positive aspects of their experience and something they could not leave behind.

#### 7.3.5 Appreciation of Art

In acknowledgement of an expectation that some participants would not have knowledge or experience in this area, an appreciation of art, or the act of interpreting or studying the images, was not a requirement for participants in this study. However, without prompting or direct inquiry from me, participants were very clear and expressive about what images they preferred and why. Participants may have been comfortable with this because I always made it clear that my role in 'Open Window' was that of a researcher and that I was not involved in its development or content. Patients also verbalised what they did not like about 'Open Window' and what they felt should be shown. Not all participants liked 'Open Window' and some expressed the view that "it wasn't for me". Others (n=19) explained that they were too sick to be interested in it, or anything! Regardless of whether participants provided negative or positive feedback on the content of 'Open Window' it appears that it perhaps, as the evidence suggests, has the potential effect of enhancing participants' overall experience of having a stem cell or bone marrow transplant in the Denis Burkitt Unit. They gave their personal views on their experience of 'Open Window' and

opinions on its content and future development. Participants also controlled this experience and many used the remote control option of de-selecting channels with content that did not appeal to them.

One of the reasons for this may relate to Benson's (1993) Theory of Aesthetic Absorption where art provides an experience that they would not have had if 'Open Window' was not available. It allowed patients to think about something outside their illness, and express an opinion, be that negative or positive. Like art in any context, it will always draw comment or conviction from the viewer (Kester 2004). Participants in this study from the Denis Burkitt unit may be described as patients with a life threatening illness and undergoing intensive treatment; however, as an art work, 'Open Window' allowed them to be individuals viewing a work of art as they would in a gallery or community setting. The difference in how participants respond to art as patients with a life threatening illness in an acute care setting compared with the general public is evident in their comments (particularly the negative) on the content. Participants seemed to understand that how they viewed things was now different and they were aware of what images concurred with the strategies they used to adjust or cope, or were meaningful to them or with their situation. For example they wanted to see bright images with plenty of colour and did not want the challenge of abstraction (section 6.4.3). The 'experience' that Benson refers to provides the medium through which patients can be individuals or 'themselves' and these experiences with 'Open Window' allow them to move through time and, in doing so, to retain a sense of self. This is essential in maintaining self esteem. Another important aspect of this is that participants controlled what they saw on 'Open Window', when they saw it and how long they looked at it; this, too, added to their sense of self and control over their environment and experiences.

Holding the unusual position of being a nurse and research fellow rather than an artist, discussing the possible role of an art intervention in a clinical setting is somewhat challenging. This is not just because of my limited (but ever

increasing) knowledge of art but because this research requires commentary on how participants in this study experience 'Open Window' both as an experience of art and an intervention in their treatment. It is also necessary at this stage to support and expand on the discussion in chapter one on why art as opposed to design has the potential to help patients psychologically.

As already discussed, the potential psychological benefit of 'Open Window' is evident in the lower scores for anxiety, depression and distress in the intervention group and the statistically significant differences between the more positive experiences of the intervention samples than the control samples in the combined groups in relation to their expectations. The differences in expectations could be attributed to the lower scores for anxiety, depression and distress reported by the intervention groups. This would suggest that although the difference was never any more than 2-3 points and not statistically significant, it may actually have had some clinical significance with even slightly lower levels resulting in participants feeling that their experience was better than expected. Interestingly, participants for the intervention groups attributed their experience being better than expected to family/friends' support, medical/nursing care and receiving information that was reassuring. However, participants in the control group also listed family/friends and medical/nursing staff as helping their experience. Due to the small sample size at this stage of the study, it is not possible to say definitively if 'Open Window' as an intervention influenced levels of anxiety, depression and distress in the intervention groups. However, the reason for this effect and the statistically significant differences between the control samples and intervention samples, which reported their experience as being better than expected, may lie in how the participants experienced 'Open Window' as art as a social and cultural experience. It is possible that the effect of this type of experience may be to increase participants' sense of well-being, and sense of self because the experience is grounded in a contemporary social and cultural concept of art that is mindful of the health care context in which it is exhibited, but yet is

unrelated to illness and from a personal or individualised perspective, seems to represent aspects of real or normal life.

### 7.3.6 'Open Window' as an Art Museum

Unlike a visit to an art museum where the art works and information are presented in a carefully considered, logical manner that reflects a specific cultural, social and political attitude (DiMaggio 1996), people that view 'Open Window' are not members of the public. They are acute care patients in a large hospital with its own very different cultural, social and political attitudes. Their knowledge of art or interest in viewing it was not elicited when recruiting them for the study. The reason for this was that in the pilot study, participants seemed intimidated by or lost interest in 'Open Window' due to their perceived lack of knowledge about art. Describing 'Open Window' as a series of photographs and video specifically curated for their environment seemed less problematic for participants. Interestingly, in their descriptions of likes and dislikes about 'Open Window', how it made them feel and how they used it, participants seemed to behave in a similar manner to members of the public visiting an art museum. Smith and Wolf (1996) conducted a survey supported by observation to examine art museum visitors' (n=609) preferences and intentions in constructing aesthetic experience. They found that visitors spent on average 15 seconds viewing an art work or, on rare occasions, viewed it for 1 minute but passed by many works without looking at them or just briefly glancing at them. The majority of visitors spent 1-2 hours in the museum. It is difficult to expect or justify the occurrence of an aesthetic experience/absorption or recognition of personal meaning in this level of engagement with an art work. However, Smith and Wolf (1996) suggest that it does occur and evidence of this is in the, on average, 3 return visits per year by the typical visitor. However, a stronger rationale for explaining the occurrence of an aesthetic experience is in how visitors construct their visit by choosing what specific gallery to visit first and locating specific images of interest to them, which is primarily influenced by their cultural, social, and educational background (Bourdieu 1990, DiMaggio 1996, Smith and Wolf 1996,

Doering 1999, Heath and vom Lehn 2004). Packer (2008) conducted a deductive qualitative study to investigate the meaning and value of a museum visit from the visitors' perspective. The findings of this study support Smith and Wolf (1996) and it concludes that museum visits can have mental restorative benefits and a positive effect on psychological well-being for visitors. Packer (2008) and Bedford (2004) attribute this primarily to the viewer's aesthetic experience although Packer acknowledges that cognitive encounters are also valued by visitors.

Participants in the 'Open Window' study demonstrated similar behaviours as visitors to an art museum. They did not spend long periods of time viewing images and ½-1 hour was the average amount of time spent viewing 'Open Window', although more frequently, unlike the typical art museum visitor, they returned to it on average 3-4 times per week. Their descriptions about the value of 'Open Window' for them and how it made them feel supports Smith and Wolf's (1996) assertion that the occurrence of an aesthetic experience is not based on time, it seems it is more supported by perception, and meaning for the viewer. A study conducted by Kotler (1999), and supported by Combs (1999) reports that visitors to art museums want a relaxing experience that removes them from their everyday world. A limitation of many visitor research studies is that they are usually conducted in one museum (Smith and Wolf 1996, Kotler 1999, Packer 2008) so this should be taken into account when interpreting the findings. However, when considered collectively, the findings from these studies appear to support each other. It seems feasible, therefore, to suggest that if engagement at some meaningful level did not occur between the participants and the content of 'Open Window' it is unlikely that they would have returned to view it 3/4 times per week or reported the benefits of distraction and connection in the outside world that they experienced.

Heath and vom Lehn (2004) conducted an ethnographic, observational study that explored the way in which interaction between visitors in museums may enhance

their experience of the art objects by creating opportunities for discussion. The findings of their observation suggest that, although, as indicated by Smith and Wolf (1996); visitors shape their own experience, interaction with others while viewing the same object also shapes and alters the experience. Although this was not a topic for discussion during interviews in this study, it is interesting to note that family members usually joined in discussions about 'Open Window', offering their views on it. In addition, my field notes refer to a conversation I had with one of the nurse managers about how she and a patient were discussing a video piece of cows grazing with their calves. When she commented that the cows looked very thin, the patient informed her that this was normal after calving and in the ensuing conversation, the patient talked about his life working as a vet and his love of animals, particularly horses. The nurse manager commented that she usually does not talk to patients about things outside their illness and felt that 'Open Window' provided a medium for social interaction, and she also viewed the video of the cows and calves differently thereafter. This is just one example from this study of how Health and vom Lehn (2004) suggest visitors can alter each others' experience but is also particularly important because it illustrates a distinction between the role of art in health care contexts versus art in museums and communities. This also supports Hodges et al's (2001) study discussed in chapter 2, which found that art can provide a medium of communication between patients and caregivers that transcends illness. Art in health care contexts helps people retain individual social and even cultural aspects of their selves.

'Open Window' seems to have similar characteristics and properties to an art museum although Kester (2004) may not agree with this supposition, as 'Open Window' could also be regarded as community art because of its location outside an art museum. However, Smith and Wolf (1996) describe three distinct elements of an art museum as the work of art, its presentation and the viewer, that interact in determining the nature of the encounter for visitors. These elements are present also in 'Open Window' and were carefully considered in its conceptualisation, development and presentation under the auspices of the



hospital management and art review committee. The concept of 'Open Window' as both an art intervention and a 'museum' seems to have some merit but, perhaps more importantly, its place in healthcare with its museum-like characteristics and qualities and its purpose as a psychological intervention challenges current thinking and practice in art in health programmes for both health care professionals and artists.

Smith and Wolf's (1996) study found that the majority of visitors were 35 years or younger, less wealthy than expected of art museum visitors but had high levels of education. In contrast, participants in this study had an older age profile and the majority had not achieved higher levels of education. An interesting point that both Smith and Wolf (1996) and DiMaggio (1996) make is that people who are well educated tend to have more exposure to culture, specifically art and art theory as a child and therefore are more frequent visitors to art museums. This may explain the aversion to the word 'art' for participants in this study. The effect of this demographic on how culture and, specifically, art museums and galleries are viewed by the general public is explained by Pierre Bourdieu's (1984) theory of social and cultural reproduction. He proposes that knowledge and appreciation of the visual art and sculpture found in museums represents an elite sociodemographic profile. This theory is supported to a greater or lesser degree in studies by DiMaggio (1996) and Smith and Wolf (1996). However, Bourdieu (1984) also says that the lower socioeconomic groups or less well educated do not enter museums or appear to not value fine art because they do not like it. It is its context and fear of being 'out of place' that limits their interest or engagement with art. Wright (1995) suggests that this is why popular art available in many different forms in TV, video, advertising and youth culture are so widely accepted. They are available to all in all socioeconomic contexts. This theory goes some way towards explaining how 'Open Window' as a museum or gallery functions so successfully. It appears as a screen, which is controlled by the viewer using a remote control and is experienced in the realm of the individual's personal space, both physical and psychological.

### 7.3.7 'Open Window' and the Environment

One of the aims of 'Open Window' was to enhance or provide an ambient environment. Participants in this study did not identify this as one of the characteristics they valued or recognised. The previous discussion on participants' evidently strong sense of control and the theory called the Cultural Psychology of Self (Benson 2001) discussed as part of the theoretical framework for this study in chapter 2 may help explain this. In conjunction with Brennan's (2001) SCT model of adjustment, this psychological theory can help understand participants' response to their environment and why levels of anxiety, depression and distress are not higher given the patients' physical and psychological situation within a restricted, clinical and isolated environment. Benson's (2001) theory of the cultural psychology of self, which is supported by Cole (1999), suggests that there is a fundamental link between the places that human beings occupy and how sense of self provides stability in these ever changing and evolving environments. It would seem logical, therefore, to suggest that patients in the very clinical, isolated and often alien environment that is the Denis Burkitt unit would experience higher levels of anxiety, depression and distress; however, as the literature and this study confirm, they do not. This suggests that patient's sense of self is quite strong even though they cannot exert any control over their environment; they perceive that they still have control over their lives, which explains the strong sense of positive psychological adjustment that emerged from this study (Brennan 2001). Personal self development occurs through interaction and relationships with others regardless of the context. This is supported by the qualitative data in which it can be seen that participants are equally concerned with practical issues or problems with their environment as they are with its aesthetic appearance, and it was family and friends and medical/nursing staff that lay at the center of how they dealt with stress, retained a sense of control and expectations of their future and perceptions of their overall experience. In fact, many describe the environment as clinical and functional, but it was this and its cleanliness that made them feel safe. The implication is that outside its function

of meeting physical needs, containing the necessary equipment and technology and preventing infection, other aspects of their environment were of less concern.

Many participants in this study described their environment as ‘prison like’. Interestingly, and contrary to what I expected, this was not just the allogeneic groups, who generally spent twice as long in protective isolation than the autologous groups, which verbalised this. All groups commented fairly equally with only slightly more in the allogeneic groups commenting on this. However, in the course of listening to the interviews and reading transcripts I got the perception that the isolation or duration of treatment and confinement was more of an issue for participants in the allogeneic groups. When I explored the qualitative data further using NVivo query tools, it became apparent that this was not the case. I felt this was an example of where my preconceptions about enduring this type of environment for long periods of time could have influenced the interpretation of the data and if I were working as a health care professional with these patients, may influence how I cared for them.

#### **7.4 Long Term Effect of ‘Open Window’**

From the results and ensuing discussion it is perhaps premature but feasible to suggest that ‘Open Window’ has a short-term effect on participants’ experience of having a stem cell or bone marrow transplant and, even though it does not currently, it may prove in time to have a psychological effect. This study also attempted to ascertain if ‘Open Window’ had a longer-term psychological effect on patients. As with all seven data collection points over the six month period, repeated measures ANOVA indicates little or no difference in levels of anxiety, depression or distress between the groups at the six month stage post transplant. The lower scores for anxiety, depression and distress in the intervention groups are not statistically significant. When interviewed at T7 many participants acknowledged that they either did not or consciously tried not to think of the Denis Burkitt Unit and, by implication ‘Open Window’. It was interesting to note, however, that six participants indicated that their interest in art had

increased somewhat since their experience and provided explanations to support this assertion. Others commented that although they had not developed an interest in art, they still had positive memories of ‘Open Window’ or were reminded of it unexpectedly when they looked at certain scenes, particularly of nature. Two patients talked about how they would choose different images of familiar places if they were back in the Denis Burkitt unit. They were able to identify these places and had clearly spent time thinking about their preferences. Participants from both allogeneic and autologous groups still talked about recovering and none had returned to work at T7. Even though it appears that on a subjective level, ‘Open Window’ has the ability to increase awareness or interest in art, it is possible that six months is too soon, as many studies indicate that pre-transplant levels of personal, social, and professional functioning do not occur for up to one year post transplant (Hjermstad et al. 1999, Fife et al. 2000, Syrjala et al. 2004, Rusiewicz et al. 2008).

## **7.5 Methodological Issues**

### **7.5.1 Study Design**

Even at this interim phase of the ‘Open Window’ study, it is clear that the randomised controlled trial design with mixed methods for data collection and analysis has worked very well in meeting the aims of this study. The main strength of this design is its ability to elicit information that provides a unique contribution to both art in health practice and the provision of patient-centred care. The quantitative data demonstrate any effect that occurs and the qualitative data provide possible explanations for this effect. This is particularly evident in participants’ comments on the importance of the physical presence of immediate family to their experience and also how participants engaged with and felt about ‘Open Window’. It is the high level of engagement that suggests that participants experienced it as a social and cultural event, which like any member of the public attending an art museum, has a positive influence on their sense of

well-being and sense of self. However, although the randomised controlled trial design of this study has the potential to provide compelling evidence that this is the direction in which further research needs to be focused, it is beyond the ability of this study at this interim phase to comment on this further.

### 7.5.2 HADS and DT

As discussed in chapter 3 the HADS and the DT are commonly used HRQoL instruments when assessing quality of life in cancer studies. However, the findings of this study and indeed many others suggest that anxiety, depression and distress may not be the most appropriate outcomes to measure as indicators of quality of life. The consistently low to moderate scores evident over time in these studies and supporting qualitative data strongly suggest that family and the ability to engage in simple activities of normal life are the primary factors that influence how an individual perceives their quality of life. This raises a challenge for researchers in terms of how to measure this or even if it is possible to measure. Perhaps subjective accounts need to be elicited from all quality of life studies in order to build a body of knowledge that can contribute to helping health care professionals involved in this research to gain a different understanding of quality of life. As a result of conducting this study and reviewing the literature, I, as a researcher feel that quality of life as a measurable entity based on current definitions is questionable. It is apparent that measuring levels of anxiety, depression and distress is perhaps irrelevant when assessing quality of life in this population. As a health care professional also, I now recognise my own biases in relation to cancer diagnosis, treatment and recovery and understand how the presence of similar biases in health care professionals can influence the type of care patients receive and also the outcomes chosen by researchers when designing quality of life studies in cancer patients.

This also became apparent during the pilot phase of the study when I found conducting the interviews particularly challenging (5.9.1). In hindsight, it was

not primarily my inexperience in interviewing that caused the difficulties for me, it was also my own discomfort with conversations about living with a life threatening illness and dying. It became apparent to me very quickly that the main concern of people with a life threatening illness was maintaining family and social relationships. Receiving treatment and having a good, successful recovery was also extremely important to them but it was their relationships with family and returning to a normal life in particular that was central to a perceived good quality of life.

As a researcher I was also mindful of the vulnerable situation that the participants were in and this may also have influenced how I conducted the early interviews. However, I became aware that if I used active listening skills, participants seemed to relax and talk more openly. Once I overcame my own anxiety about discussing the possibility of their death as a result of the treatment and also seeing their physical distress, I was able to respond in a more empathetic manner. This has implications for researchers working with populations that have chronic or life threatening illnesses because it is clear that introspection and the development of self-awareness is essential if the researcher is to elicit detailed, comprehensive, subjective accounts of patients' experiences. I feel that the experience of conducting these interviews has enhanced my ability to truly empathise with others and given me a greater understanding of the strength and support that people draw from interpersonal interaction in developing and retaining a sense of self and well-being.

### 7.5.3 'Open Window' Questionnaire

The 'Open Window' survey questionnaire was helpful in that it highlighted how the participants from the intervention groups felt about it (Appendix 6). However, reliability testing using a correlation matrix showed that, as anticipated, due to the absence of a latent construct throughout the questionnaire or within the sections, correlation between the items was poor (Appendix 6a). Future development of this questionnaire will be a great deal more informed due to the qualitative data provided by this study. Items in each section will relate to

a single construct, for example, distraction, connection or appreciation of art. Further research that is expected to be conducted in other sites that will be providing and evaluating 'Open Window' to a similar population will facilitate further development and testing of this survey questionnaire.

#### 7.5.4 NVivo

NVivo proved to be very useful package not just for storing and managing data but also for testing assumptions and interpretations of data. In the process of qualitative data analysis, my own personal biases and prior beliefs influenced my understanding of the data, and without NVivo may have also resulted in inaccurate interpretation. This has implications even for purist qualitative researchers who are perhaps more concerned with personal biases and prior beliefs. This package facilitated the transparency of the mixed method design of this study by its ability to produce tables, graphs and concept maps that presented subjective data clearly and in support of my interpretation of the data.

#### 7.5.5 Study Population

This study took place in an acute care setting where participants were admitted and recruited to the study when they were feeling very well physically. They quickly became extremely ill in many cases due to the intense treatment and side effects of medication. As the questionnaires, psychometric tools and interviews were administered and conducted by the same researcher, missing data is minimal. That perhaps is not so much the issue as the participants' ability to engage fully with 'Open Window'. Many commented (n=19) that they were too sick to view 'Open Window' at all or did not view it for significant period of time during their time in the Denis Burkitt Unit. The problem could be more significant than this, with many participants not commenting. For this reason, this population may not be the most appropriate on which to test the psychological effect of 'Open Window'. That said, it is also feasible to suggest that any positive effect seen in this study could imply an even greater effect in a less compromised population.

Both qualitative and quantitative findings from this study suggest that psychological and physical differences between the allogeneic and autologous groups are absent or minimal. This is supported by many studies that do not separate these groups when conducting quality of life research on patients undergoing stem cell or bone marrow transplantation and those that do report minimal differences in outcomes. This implies that stratified sampling and randomisation may not be necessary, with the issues concerning participants being psychosocial rather than medical with the common factor between them being the experience of having, and being treated for, a life threatening illness.

#### 7.5.6 Limitation

As discussed in chapter 4, blinding is a key factor in preventing bias in randomised controlled trials. However, this is not possible in studies measuring the psychological effect of an intervention such as ‘Open Window’ as although the randomisation process and sequence is blinded, the outcome is obvious to each participant and the researcher due to the presence of the technology in certain rooms only and the requirement to view the content in order to measure and explore its effect. It is possible, therefore, that preconceived ideas and subjective accounts may reflect a small element of bias; however, this is limited as the actual level of participation required by the participants very much reflects clinical practice or non-trial conditions of the intervention.

## 7.6 Summary

The results of the repeated measures ANOVA tests on the HADS and DT indicate that at this interim phase of the study, even though the intervention groups had lower scores for anxiety, depression and distress, these are not statistically significant. However, when the results for the intervention samples and control samples from the autologous and allogeneic groups are analysed together the difference in the ‘better than expected’ experience reported by the



intervention samples is statistically significant. Interestingly, this finding suggests that 'Open Window' has a positive effect on participants' overall experience of undergoing stem cell or bone marrow transplantation. However, at this interim phase of analysis definitive statements cannot be made.

A clear pattern in the changes in levels of anxiety, depression and distress over a six month period emerged from the data. The highest scores for all groups were observed at T1 and continued to T4 where they began to drop to low-moderate levels. Even at their highest score, participants did not generally exceed the cut-off scores that indicate the need for medical/psychological intervention. The similarity between scores of the allogeneic and autologous groups suggests that stratified sampling and randomisation may not be necessary.

Qualitative data reveal that participants in this study did not experience high levels of stress and even the 1/3 that perceived they did not have any control over their lives or situation did not view this negatively. Family and friends were regarded as the greatest source of support with the experience of having a transplant resulting in better relationships. Low to moderate levels of anxiety, depression and distress support the qualitative data and concur with literature suggesting that quality of life is more associated with social and philosophical aspects of life than health or physical symptoms. This highlights the need for more self-awareness and understanding of these issues on the part of health professionals in assessing and meeting the psychological needs of patients.

The quantitative and qualitative data support the theoretical concepts underpinning this study. This is evident in the relationship between positive adjustment and perceived level of social support and control. If present, this maintains a strong individual sense of self and self-esteem as proposed by Brennan's (2001) SCT model of adjustment.

Participants in this study reported positive experiences with ‘Open Window’ and the statistically significant results of the expectations questionnaire suggest that its effect may lie in how it influences a patient’s whole experience of having a transplant. More participants from the intervention groups reported that their experience of having a transplant was better than expected. Also in support of the Theory of Aesthetic Absorption (Benson 1993) and the Cultural Psychology of Self (Benson (Benson 2001), participants describe the value and benefit of ‘Open Window’ as its ability to distract and provide a sense of connection with the outside world. The almost unconscious process of art appreciation provided a cultural, social and personal experience that each participant controlled, similar to a visit to an art museum/gallery.

Although many participants in this study, from all groups, commented on the ‘prison like’ qualities of their environment, it did not induce negative emotion. Some actually felt safe in the environment and felt that its clinical nature was reassuring in terms of meeting their needs when receiving intense treatments. Practical problems with the environment were of more or equal concern than was its aesthetic appeal.

Repeated measures ANOVA indicate no statistically significant long term psychological effect of ‘Open Window’ on levels of anxiety, depression or distress. A small number of participants in the study commented that their interest in art had increased as a result of their experience of ‘Open Window’ and many still thought about it six months after their transplant.

## **7.7 Conclusion**

The clinical trial design using mixed methods for data collection and analysis provided information that allowed me to explain and discuss results in a comprehensive manner. It not only showed that ‘Open Window’ may not have an effect on participants’ levels of anxiety, depression or distress over time but it appears to have a statistically significant effect in how it influences a patient’s

overall experience of having a stem cell or bone marrow transplant. The qualitative data complement this very well in explaining how it may have influenced their experience and also in explaining the nature of the participants' experience with 'Open Window'. This is relevant to both the art and medical world.

The conceptualisation, development, content, presentation and use of 'Open Window' is user friendly and maintains the integrity of art and its aesthetic construction similar in ways to the qualities and experiences of an art museum.

The theoretical concepts used to contextualise this study emerged as useful and appropriate in explaining and discussing the findings. They acknowledge the individual nature of the psychological response to being diagnosed with, and receiving treatment for, a life threatening illness. In conjunction with the results from this study, they highlight the importance, as health care professionals, of reframing our understanding of quality of life as a personal construct that has control, family and 'normal life' at its centre. Physical illness may influence this construct but perhaps only in how it is perceived by the individual in affecting their level of control, family relationships and their ability to live a normal life.

## **7.8 Implications**

The findings of this study suggest that, even though more participants from the intervention group than the control group perceived that they had a better experience than expected, this did not seem to have a corresponding effect on levels of anxiety, depression or distress. As reported with many cancer studies, levels of anxiety and particularly depression are usually below those requiring specific intervention or medication anyway but the difference between the intervention and control groups in this study was very small and statistically insignificant. It is possible that because participants in this study appear to adjust well psychologically to undergoing stem cell and bone marrow transplantation, anxiety, depression and distress may not be the most appropriate outcomes to

measure in determining the potential psychological effect of an art intervention such as 'Open Window'. Psychometric tools such as the Profile of Mood States questionnaire may be more appropriate and revealing. Although this questionnaire is available and tested in its long (67 items) and short (30 items) version, consideration of the burden of such questionnaires is of paramount importance as many require attention that is beyond the capabilities of patients undergoing intensive treatment for cancer.

The findings of this study highlight significant implications in the level of self-awareness that health care staff have in relation to the diagnosis, treatment and recovery from a life-threatening illness. Providing patient-centred care may prove difficult if health care staff and patients have different perceptions of the process involved in adjusting positively to these experiences. In order to empathise effectively and therapeutically, it appears that self-awareness in relation to these issues is essential. This is an issue for the under-graduate and post-graduate education of all health care staff.

The importance of family support in helping patients adjust positively to cancer diagnosis, treatment and recovery, highlighted in this study implies that health care professionals need to recognise and understand the importance of family to patients' psychological care. This recognition and understanding can be communicated to patients through the manner in which family members are supported and made to feel welcome and comfortable through simple environmental facilities such as, access to beverages and comfortable chairs.

Further testing on different populations, perhaps with chronic illness, rehabilitation units or, as has been suggested at the current research site, patients with respiratory TB in isolation while receiving treatment would support these data. However, residential homes may also be suitable where it is expected that the psychological and physical issues would be less intense and 'Open Window' could be viewed in a more consistent manner.

As it is clear from the qualitative data and the low to moderate levels of anxiety, depression and distress that persist at the six month stage (T7) of data collection, recovery is still very much an ongoing process, so an additional interview 12 months after the transplant may give a clearer picture of participants long term views on 'Open Window' and if it increases their interest in art.

The value of the qualitative data for explaining and providing meaning, not just to 'Open Window' as a treatment intervention, but also to the results of the psychometric tools is clear from this study. In teaching students about research, it has traditionally been presented in purist philosophical and methodological terms such as qualitative or quantitative designs, which is perhaps no longer relevant.

## **7.9 Recommendations**

- As a result of the unexpected emergence of 'Self and Others' as a new and very important theme from the qualitative data, a meta analysis looking at the conceptual understanding of meaning, coping, and adjustment in cancer patients is recommended. This would facilitate the bringing together of information that may appear distinct but is actually perhaps quite closely related in explaining how individuals respond to cancer diagnosis and treatment.
  
- It is recommended that more emphasis be placed on the key role of family support in helping patients adjust psychologically to being diagnosed with and treated for cancer. This needs to start at under-graduate and continue at post-graduate education level for all relevant health care professionals. Studies such as this provide subjective and objective data explaining the nature of this support and may help health care professionals develop a more patient-centred understanding of living with a life threatening illness. This type of understanding should translate into a more patient-centred approach to treatment and care.

- Further research exploring the nature of the role of family support in helping individuals adjust psychologically to cancer diagnosis and treatment is recommended in order to provide sufficient evidence to effect change in the environmental conditions provided for patients with life threatening illness and their families.
- As a result of the consistently low scores for levels of anxiety, depression and distress seen in this study and others, it is recommended that other psychometric tools be considered when assessing quality of life in patients with a life threatening illness, for example, the profile of mood questionnaire (Lorr et al. 2003) may have been quite useful for this study. It may also be more appropriate to assess individual family and social relationships in determining quality of life in patients with a life threatening illness such as cancer.
- It is recommended that evaluation of medical and non-medical interventions such as ‘Open Window’ be conducted using mixed method research designs. Without obtaining subjective accounts of patients’ experiences of these interventions in conjunction with objective measurement of their effect, it is more difficult for health care professionals to understand their meaning and therefore translate outcomes of these studies into practice and the provision of patient-centred treatment and care. It appears from this study and others that only mixed methods approaches to research can increase knowledge of how medical and non-medical interventions affect patients from a holistic perspective.
- It is further recommended that mixed methods research with its specific underlying philosophy of pragmatism is given equal consideration at third and fourth level education.
- In conclusion, given the lack of evidence of any adverse effects of ‘Open Window’ on participants in this study, it is recommended that this trial be continued until the *a priori* sample size has been achieved.

The findings of this study demonstrate the potential value of rigorous approaches to research in the evaluation of art as an intervention in health care contexts. Evidence of the potential psychological effect of art and subjective accounts of its value provide an insight into the unique, unstoppable response to art that illustrates patients' individualism and sense of self. This study demonstrates how even patients with a life threatening illness, undergoing intensive treatments, retain the ability and need to reflect on, and respond to life outside their illness. 'Open Window' is a patient-centred art intervention, the content of which reflects an understanding of the nature of living with a life threatening illness by distracting patients and connecting them with the outside world, but also, like any art work, by demanding a human response, provides personal and evolving experiences in health care contexts that can be otherwise, clinical and functional.

## **Appendices**



## **Appendix 1: Denis Burkitt Unit**





## **Appendix 2: 'Open Window' Images**





### **Appendix 3: Study Protocol**

## **Study Protocol**

### **The ‘Open Window’ Project**

**An evaluation of the effect of ‘Open Window’, an art intervention, on psychological well-being and experience of stem cell transplantation for the treatment of haematological malignancies**

June 2006



## **Trial Organisation**

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## **Participating Centre**

Denis Burkitt Unit, St. James's Hospital, James's Street, Dublin 8

## **Sponsors**

Irish Cancer Society

Vodafone Foundation, Ireland

Bone Marrow for Leukaemia Trust

## **Introduction**

This protocol is for a 4 group randomised control trial to evaluate the effect of the 'open window' on the effect of long term isolation on patients undergoing treatment of haematological malignancies. This study uses a randomised control trial design, which is widely used in healthcare settings to test the effects of interventions and testing cause and effect relationships between variables. A mixed methods approach for data collection and data analysis will be used. This will facilitate measurement of patients' psychological response to 'Open Window' using questionnaires and exploration of subjective feelings in relation to their experience of having a stem cell transplant through semi structured interviews.

## **Hypothesis to be tested**

'Open Window' does not have an effect on patient levels of anxiety, depression or distress when undergoing a stem cell transplant.

## **Background**

'Open Window' is a unique and novel intervention for patients being treated for haematological malignancies in the 'National Stem Cell Transplant Unit', St. James' Hospital, Dublin, Ireland. Treatment programmes include allogeneic and autologous stem cell transplantation for leukaemia and related disorders. This unit comprises 21 single air-conditioned rooms in which patients are treated and cared for. The unit is located on the ground floor of a large hospital and the view out of most of the windows is limited to the light railway system at best and the air conditioning unit at worst. Windows in the rooms are quite large although light and sunlight is limited in some by an adjacent building. The rooms vary in

size and shape and all are en suite and contain a bed, locker, easy chair and TV/video mounted high on the wall, usually to the left, in front of the patient. All rooms are painted in magnolia with a blue door to the en suite and exit. In order to reduce the risk of infection, flowers and pictures hanging on the walls are prohibited and personal items such as photos are limited. Blinds are used on the windows and bed covers are blue, pink or green. The overall effect is minimalist and clinical due to the presence of medical equipment. Visiting is limited and children under 14 years of age are not allowed to visit.

Although a new unit, The National Transplant Unit was not purpose built and the focus of the design was in providing a protective environment for as many patients as possible within a limited space and with very specific requirements. While it is arguable that the introduction of colour to the walls and the inclusion of patterned curtains or bedspreads might enhance the environment from a design perspective, in the absence of such an initiative, this atmosphere provides an ideal opportunity to assess the effect of art on the experience of a very specific group of patients in a controlled atmosphere. Redshaw (2004) suggests that design alone does not provide spaces that are attractive, imaginative and engaging but that it is the inclusion of art that does this. Her study on the impact of the provision of art in a children's hospital is reported as providing a distraction for children and parents, providing enjoyment and comfort, facilitating self-expression and building self-esteem and confidence. This function of art in healthcare fulfills its role in providing a healing environment and is the primary reason why it was considered an appropriate intervention for the specific population of patients included in the 'Open Window' project.

People have a basic need for contact with each other. Isolation from people, or separation from familiar places, can cause feelings of despair, anger and hopelessness (Denton 1986; Jenner 1990; Gammon 1998). Views of nature or people through a window reduce the negative effects of isolation and can impact positively on psychological well-being (Kennedy & Hamilton 1997, Ulrich 1983). Due to the location, design and décor of the rooms, the patients in 'The National Stem Cell Transplant Unit' at St. James's have very little stimulation other than TV, radio and reading. It is arguable that a patient centred hospital environmental design may be sufficient to make their experience more comfortable and aesthetically pleasing; however, it is the inclusion of art in the environment that may provide a more positive and enduring distraction for patients and have a positive influence on a patient's sense of 'self' and well-being and overall psychological adjustment to having a life threatening illness. This is important in providing holistic care for patients and may influence their immediate and long-term recovery.

'Open Window' is an entirely art based intervention comprising a multimedia system that uses a combination of video projectors, audio speakers and bespoke software to make images appear as a 'virtual window' on the wall of the patients' room. Artists use mobile phone cameras and camcorders to record the images that are sent to the unit over the internet and via mobile phone networks.

Original music composed for the project may also accompany the images as they appear. The curator and artist in residence on the project can discuss with the patient and family, the possibility of obtaining familiar and/or family images if they wish. Patients can turn the system on, off and change the images by pressing the appropriate button on the remote control. They can also choose to include or exclude certain images if they wish. The volume of the music that accompanies some of the video channels can be controlled using the remote control.

Artists are commissioned to create work for the 'Open Window' project and are aware of the nature of the viewer and the context in which the art will be shown. The art in 'Open Window' encourages the viewer to think about and engage in what they see from their own personal frame of reference. The artist and theorist, Duchamp (1957, 3) described this process as the viewer "bringing the work in contact with the external world by deciphering and interpreting its inner qualification". These principles give patients who wish to use 'Open Window' the opportunity to become part of the creative process regardless of their past experience or knowledge of art. Patients may benefit because 'Open Window' becomes whatever they want it to be and helps them deal with their physical, psychological and social needs in a unique and individualized way.

The 'Open Window' Intervention has three aims. The first is to help patients deal with being in a restricted protective environment for 4-6 weeks. The second is to give patients a sense of connection with the outside world and the third is to provide a medium through which patients may reflect on having a life threatening illness, which may have immediate, and long-term effects on their psychological adjustment to recovering from and possibly surviving stem cell transplantation.

## **Study Design**

### **Trial Eligibility**

Inclusion criteria:

- Any patient admitted to the Denis Burkitt unit for an autologous or allogeneic stem cell transplant.
- Patients aged 16 years or above
- Any patient who gives informed consent to participate in the study
- Has not experienced 'Open Window' on a prior admission.
- Can read and speak English reasonably well.
- Does not have communication difficulties, intellectual disabilities or known mental illness
- Will be treated as an in-patient in the Denis Burkitt Unit following transplantation.

Exclusion criteria:

- Patients who are not undergoing a stem cell transplant
- Any patient who does not consent to participate in the study
- Any patient with communication difficulties, learning disabilities, mental illness, prisoners, young offenders.
- Patients who have experienced ‘Open Window’ on a prior admission.
- Patients who are transferred to other units immediately following transplantation

### **Recruitment and Trial Entry**

Recruitment will require teamwork between the research team and the nursing/medical staff on the Denis Burkitt Unit. Experience suggests that it is important that clinical staff understand the background and purpose of the study and recognise the potential of the intervention for improving patients’ sense of well-being and overall quality of care. Information sessions, equipment demonstrations, posters/leaflets, written instructions and this protocol will be provided for all staff on the Denis Burkitt Unit. The researcher will visit the unit frequently and keep the staff informed of the study progress through newsletters and the project website, [www.openwindowproject.org](http://www.openwindowproject.org).

The transplant co-ordinators will recruit participants for the study prior to their admission. Information leaflets informing all eligible patients of the background/purpose/details of the study and a letter inviting them to participate will be given to all eligible patients that are booked into the Denis Burkitt Unit for treatment. Each patient will have a minimum of 14 days to consider the information and decide if they want to participate in the study. They are also given an opportunity to discuss the information with the researcher over the telephone if they wish. If they agree to participate they are asked to provide written consent. When they give consent, the transplant co-ordinator phones the telephone randomisation service and each participant will be randomly allocated to a room with the ‘open window’ technology (intervention group) or to a room without the ‘open window’ technology (control group) and a study code is assigned.

### **Group Allocation**

Participants will be allocated a study number and randomised to the intervention or control group on a 1:1 ratio. Stratified Randomisation will occur using an independent telephone randomisation service. Patients undergoing an autologous stem cell transplant will be randomised separately to those undergoing an allogeneic stem cell transplant. This results in a total of 4 groups in the study. Each participant’s study number and group allocation will be recorded on the front of their case notes.

The intervention group will receive standard care and will have access to the intervention ('Open Window' technology) in their room. The control group will receive standard care in a room that does not have access to the intervention ('Open Window')

### **Measures of Outcomes**

The effect of 'Open Window' on patients' will be measured using the outcomes of anxiety, depression and distress.

4 Questionnaires will be administered to participants:

- Hospital anxiety and depression scale (Zigmond & Snaith 1983)
- Distress Thermometer
- Single item questionnaire in relation to their perceptions of their experience of having a stem cell transplant.
- 'Open Window' Questionnaire (only to the intervention groups)

A percentage of the participants from both groups will also be required to take part in semi-structured interviews. The issues addressed in these interventions relates to particular issues that emerge from relevant literature and that the research team consider pertinent.

### **Interview Guide**

#### Control and Intervention Group

- Expectations
- Physical Environment
- Control
- Stress

#### Intervention Group

- Views about 'Open Window'
- Likes/Dislikes
- How it made them feel
- Overall experience of 'Open Window'

This aspect of data collection will complement the quantitative data by facilitating the discussion of participants' thoughts, feelings and perceptions on being in isolation and the influence of the 'open window' in the room. The interviews may also result in new data not included in the questionnaire or anticipated emerging

## Data Collection

The questionnaires are regarded as straightforward, however, due to patient burden, they will be administered by the researcher and all interviews will be conducted by the researcher.

Quality control initiatives include regular data verification and protocol compliance checks that will be conducted by the researcher. Training and support will be provided for all grades of staff involved in delivering the intervention, randomisation and data collection.

### Data will be collected at the following intervals:

Data Collection	HADS	DT	'OW' Questionnaire	Expectations Questionnaire	Interview
T1 (admission)	√	√			√
T2 (Day-1)	√	√			
T3 (Day+7)	√	√			
T4(Day+18 for allogeneic and 14 for autologous group)	√	√	√		√
T5(Day+60)	√	√			
T6(Day+100)	√	√		√	
T7(6/12 post transplant)	√	√			√

## Data Analysis

Quantitative data will be analysed using 'The Statistical Package for the Social Sciences' (SPSS) Version 11. Descriptive statistics and sub-group analysis will be used to provide baseline information and identify significant differences between the study groups. Comparisons between the experimental and control group will be made using appropriate standard statistical methods.

Qualitative data analysis will be inductive using the constant comparative method of analysis and with the assistance of the computer software package NVivo. Initial analysis will be reviewed and discussed by the project team for critical comments. Following this, categories and initial themes that emerge will be tested against the data (Mariano 1995).

## Sample size estimates and assumptions

In order to test the null hypothesis that the two group means are equal the criterion for significance ( $\alpha$ ) has been set at 0.050. The test is 2-tailed which

means that an effect for either group will be interpreted. With the proposed sample size of 100 for the 4 groups, the study will have a minimum power of 80.1% to yield a statistically significant result. This computation assumes that the mean difference is 10.0 points and the common within-group standard deviation is 19.6 (Keogh et al 1998).

The number of patients eligible and willing to participate in studies relating to psychological adaptation following diagnosis and treatment for haematological malignancies appears to be high. Approximately 60% (n=125) of patients admitted to the study centre per year will undergo a stem cell transplant. Sixty undergo allogeneic transplantation and 65 undergo autologous transplantation. In a study by Keogh et al (1998) 100% (n=28) of patients agreed to participate in a study that explored the psychosocial adaptation of patients and families following bone marrow transplantation. A study by Hayden et al (2004) that assessed the long-term quality-of-life status after sibling allogeneic stem cell transplantation achieved a 90% response rate. Both of these studies were conducted in the same centre as this study. Studies by So et al (2003) and Kiss et al 2002 also achieved response rates of 70.9% and 93% respectively. However, these studies indicate that there is an incompleteness rate of between 50% and 30% in this population. Therefore, based on this data it is conceivable that between 70% and 100% of the eligible population would be willing to participate in a study evaluating the effect of an intervention ('Open Window') on their psychological well-being and overall experience of having a stem cell transplant. These estimates and a data collection period of 3.5 years suggest a total recruitment of approximately 400 patients. This sample size also allows for a power of 80.1%.

### **Protection of the participants**

Information about this study will be made available to all eligible patients prior to their admission to the Denis Burkitt Unit. The purpose of the study, possible risks and benefits to the participants, data collection procedures, confidentiality, time commitment, voluntary participation and the researchers contact details are provided in this information. Patients are invited to participate in the study once they have read this information. If they agree to participate, they are asked to sign two copies of the consent form and return one to the researcher in the stamped addressed envelope provided and keep a copy for their own records.

Participant confidentiality will be maintained by assigning each participant with an individual number, which will appear on all data collection instruments and transcribed interview data. Only the researcher will have details of the number assigned to each participant. All study data will be collected by the researcher and stored in accordance with the Data Protection (Amendment) Act (2003). Permission to conduct this study has been granted by the 'Patient Advocacy Committee' at St. James's Hospital. Ethical approval for this study has been granted by the Joint SJH/AMNCH Research Ethics Committee.



**Appendix 4: Hospital Anxiety and Depression Scale**

# Hospital Anxiety and Depression Scale (HADS)

nferNelson  
understanding people

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and underline the reply which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

<p>A 3 B 2 C 1 D 0</p> <p>3 2 1 0</p> <p>3 2 1 0</p> <p>3 2 1 0</p> <p>3 2 1 0</p> <p>3 2 1 0</p> <p>3 2 1 0</p> <p>3 2 1 0</p>	<p><b>I feel tense or 'wound up'</b> Most of the time A lot of the time From time to time, occasionally Not at all</p> <p><b>I still enjoy the things I used to enjoy</b> Definitely as much Not quite so much Only a little Hardly at all</p> <p><b>I get a sort of frightened feeling as if something awful is about to happen</b> Very definitely and quite badly Yes, but not too badly A little, but it doesn't worry me Not at all</p> <p><b>I can laugh and see the funny side of things</b> As much as I always could Not quite so much now Definitely not so much now Not at all</p> <p><b>Worrying thoughts go through my mind</b> A great deal of the time A lot of the time Not too often Very little</p> <p><b>I feel cheerful</b> Never Not often Sometimes Most of the time</p> <p><b>I can sit at ease and feel relaxed</b> Definitely Usually Not often Not at all</p>	<p><b>I feel as if I am slowed down</b> Nearly all the time Very often Sometimes Not at all</p> <p><b>I get a sort of frightened feeling like 'butterflies' in the stomach</b> Not at all Occasionally Quite often Very often</p> <p><b>I have lost interest in my appearance</b> Definitely I don't take as much care as I should I may not take quite as much care I take just as much care as ever</p> <p><b>I feel restless as if I have to be on the move</b> Very much indeed Quite a lot Not very much Not at all</p> <p><b>I look forward with enjoyment to things</b> As much as I ever did Rather less than I used to Definitely less than I used to Hardly at all</p> <p><b>I get sudden feelings of panic</b> Very often indeed Quite often Not very often Not at all</p> <p><b>I can enjoy a good book or radio or television programme</b> Often Sometimes Not often Very seldom</p>	<p>A 3 B 2 C 1 D 0</p> <p>3 2 1 0</p> <p>3 2 1 0</p> <p>3 2 1 0</p> <p>3 2 1 0</p> <p>3 2 1 0</p> <p>3 2 1 0</p> <p>3 2 1 0</p>
---	---	--	---

Now check that you have answered all the questions

TOTAL

A D

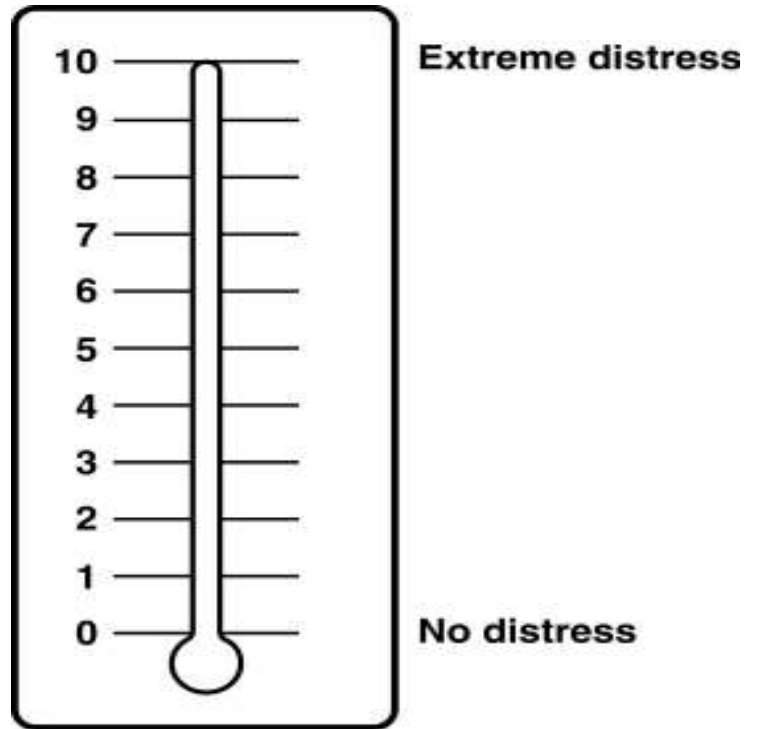
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Code: HADS(21)

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## **Appendix 5: Distress Thermometer**

**FIRST:** Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.



**SECOND:** Please indicate if any of the following has been a problem for you in the past week including today. Be sure to fill in YES or NO for each.

YES	NO	<u>Practical Problems</u>	YES	NO	<u>Physical Problems</u>
<input type="radio"/>	<input type="radio"/>	Child care	<input type="radio"/>	<input type="radio"/>	Appearance
<input type="radio"/>	<input type="radio"/>	Housing	<input type="radio"/>	<input type="radio"/>	Bathing/dressing
<input type="radio"/>	<input type="radio"/>	Insurance	<input type="radio"/>	<input type="radio"/>	Breathing
<input type="radio"/>	<input type="radio"/>	Transportation	<input type="radio"/>	<input type="radio"/>	Changes in urination
<input type="radio"/>	<input type="radio"/>	Work/school	<input type="radio"/>	<input type="radio"/>	Constipation
			<input type="radio"/>	<input type="radio"/>	Diarrhea
			<input type="radio"/>	<input type="radio"/>	Eating
		<b><u>Family Problems</u></b>	<input type="radio"/>	<input type="radio"/>	Fatigue
<input type="radio"/>	<input type="radio"/>	Dealing with children	<input type="radio"/>	<input type="radio"/>	Feeling swollen
<input type="radio"/>	<input type="radio"/>	Dealing with partner	<input type="radio"/>	<input type="radio"/>	Fevers
			<input type="radio"/>	<input type="radio"/>	Getting around
			<input type="radio"/>	<input type="radio"/>	Indigestion
		<b><u>Emotional Problems</u></b>	<input type="radio"/>	<input type="radio"/>	Mouth sores
<input type="radio"/>	<input type="radio"/>	Depression	<input type="radio"/>	<input type="radio"/>	Nausea
<input type="radio"/>	<input type="radio"/>	Fears	<input type="radio"/>	<input type="radio"/>	Nose dry/congested
<input type="radio"/>	<input type="radio"/>	Nervousness	<input type="radio"/>	<input type="radio"/>	Pain
<input type="radio"/>	<input type="radio"/>	Sadness	<input type="radio"/>	<input type="radio"/>	Sexual
<input type="radio"/>	<input type="radio"/>	Worry	<input type="radio"/>	<input type="radio"/>	Skin dry/itchy
			<input type="radio"/>	<input type="radio"/>	Sleep
		<b><u>Spiritual/Religious Concerns</u></b>	<input type="radio"/>	<input type="radio"/>	Tingling in hands/feet
<input type="radio"/>	<input type="radio"/>	Loss of faith			
<input type="radio"/>	<input type="radio"/>	Relating to God			

**Other Problems:**

**Appendix 6: Permission from NCCN to use DT**



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Comprehensive  
Cancer  
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Fax: 412.854.7200  
www.nccn.org

April 15, 2008

Catherine McCabe, MSc  
Trinity College Dublin  
School of Nursing and Midwifery  
24 D'Olier Street  
Dublin  
18  
Ireland

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Thank you for your interest in the work of the NCCN.

Sincerely,



Lynn Cherrin, MS  
Project Assistant  
NCCN

**Appendix 7: Expectations Questionnaire**



## Open Window Study Expectations Questionnaire

1. Please rate your experience of having a stem cell or bone marrow transplant by ticking the box appropriate to you

Much worse than expected	A little worse than expected	As expected	A little better than expected	Much better than expected
-----------------------------	---------------------------------	-------------	----------------------------------	------------------------------

2. Please list 3 factors that added to your experience

---

---

---

3. Please list 3 factors that did not add to your experience

---

---

---

**Appendix 8: 'Open Window' Questionnaire**

## **‘Open Window’ Questionnaire**

**The aim of this questionnaire is to ascertain patients’ views of ‘Open Window’. Please complete all sections**

### **Section 1**

This is a list of statements to find out your views on ‘Open Window’. Please read each statement and indicate which best describes your view by placing a circle around the box which most corresponds to your view.

1. ‘Open Window’ helped me deal with being confined to my room.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

2. ‘Open Window’ did not help me deal with the experience of having a stem cell transplant

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

3. ‘Open Window’ gave me a sense of connection with the outside world

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

4. ‘Open Window’ was boring

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

5. ‘Open Window’ provided a soothing environment

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

6. ‘Open Window’ was relaxing

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

7. ‘Open Window’ provided gentle stimulation

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

8. ‘Open Window’ made me feel lonelier when I saw familiar places

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

9. 'Open Window' made me feel lonelier when I saw family images

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

10. 'Open Window' helped to reduce the boredom

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

11. The 'Open Window' images were enjoyable

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

## Section 2

This section explores which images you preferred to look at on 'Open Window'. Please read each statement and indicate which best describes your view by placing a circle around the box which most corresponds to your view

12. I preferred looking at the still images

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

13. I preferred looking at the moving images

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

14. I preferred looking at images of familiar places

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

15. I preferred looking at images of family

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

16. The music that accompanied the moving images was soothing

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

17. The music that accompanied the moving images was relaxing

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

18. I did not like any of the images

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

19. I preferred looking at TV

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree	Not Applicable
----------------	-------	-----------	----------	-------------------	----------------

**Section 3**

The section explores how you used ‘open window’. Please indicate your answer to these questions by ticking the appropriate box which most corresponds to your view.

20. I was able to use the ‘Open Window’ 

No	
----	--

 technology

21. I preferred looking at ‘Open Window’ in the:

- Morning (8am-12md)
- Afternoon (12md – 5pm)
- Evening (5.01pm – 10pm)
- Before going to sleep
- There was no set pattern

22. On the days I looked at ‘Open Window’ I looked at it for:

- Less than 30 minutes
- ½ hr – 1hr
- More than 1 hour, up to 2 hours
- More than 2 hours
- It Varied

23. I looked at ‘Open Window’:

- Every day
- 5-6 days/week
- 3-4 days/week
- 1-2 days/week
- Never

24. On the days I looked at 'Open Window' I looked at it:

- Once a day
- Twice a day
- Intermittently throughout the day
- Most of the day

**Section 4**

This section explores which type of image was most popular with patients. Please indicate the frequency with which you looked at the various types of images and listened to the music available on 'Open Window,' by placing a circle in the box that corresponds most closely to your view

25. Still images

Always (Every day)	Often (5-6 days/wk)	Sometimes (3-4 days/wk)	Seldom (1-2 days/wk)	Never	Not Applicable
-----------------------	------------------------	----------------------------	-------------------------	-------	----------------

26. Moving images

Always (Every day)	Often (5-6 days/wk)	Sometimes (3-4 days/wk)	Seldom (1-2 days/wk)	Never	Not Applicable
-----------------------	------------------------	----------------------------	-------------------------	-------	----------------

27. Familiar places

Always (Every day)	Often (5-6 days/wk)	Sometimes (3-4 days/wk)	Seldom (1-2 days/wk)	Never	Not Applicable
-----------------------	------------------------	----------------------------	-------------------------	-------	----------------

28. Family images

Always (Every day)	Often (5-6 days/wk)	Sometimes (3-4 days/wk)	Seldom (1-2 days/wk)	Never	Not Applicable
-----------------------	------------------------	----------------------------	-------------------------	-------	----------------

29. Music

Always (Every day)	Often (5-6 days/wk)	Sometimes (3-4 days/wk)	Seldom (1-2 days/wk)	Never	Not Applicable
-----------------------	------------------------	----------------------------	-------------------------	-------	----------------

30. TV

Always (Every day)	Often (5-6 days/wk)	Sometimes (3-4 days/wk)	Seldom (1-2 days/wk)	Never	Not Applicable
-----------------------	------------------------	----------------------------	-------------------------	-------	----------------

**Section 5**

This section relates to any other views that you may have about ‘Open Window’. Please add any comments that you feel are relevant.

**Thank you for taking the time to complete this questionnaire. We sincerely value the important contribution that you have made to this study.**

**Appendix 8a: Correlation Matrix for the 'Open Window' Questionnaire**



Correlations

		Q1 'Open Window' helped me deal with being confined to my room	Q2 'Open Window' did not help me deal with the experience of having a stem cell transplant	Q3 'Open Window' gave me a sense of connection with the outside world	Q4 'Open Window' was boring	Q5 'Open Window' provided a soothing environment	Q6 'Open Window' was relaxing	Q7 'Open Window' provided gentle stimulation	Q8 'Open Window' made me feel lonely when I saw familiar places	Q9 'Open Window' made me feel lonely when I saw family images	Q10 'Open Window' helped to reduce the boredom	Q11 The 'Open Window' images were enjoyable	Q12 I preferred looking at the still images	Q13 I preferred looking at the moving images	Q14 I preferred looking at images of familiar places	Q15 I preferred looking at images of family	Q16 The music that accompanied the moving images was soothing	Q17 The music that accompanied the moving images was relaxing	Q18 I did not like any of the images	Q19 I preferred looking at TV	
Q1 'Open Window' helped me deal with being confined to my room	Pearson Correlation Sig. (2-tailed) N	1 0.00 36	-.138 422 36	.613* 0.00 36	-.402* 0.01 36	.536* 0.00 36	.558* 0.00 36	.607* 0.00 36	.090 0.661 26	.263 0.410 12	.635* 0.000 36	.611* 0.000 36	.274 106 36	.367* 0.028 36	.344 0.092 25	.642* 0.018 25	.170 0.321 36	.226 0.185 36	-.598* 0.000 36	-.288 0.089 36	
Q2 'Open Window' did not help me deal with the experience of having a stem cell transplant	Pearson Correlation Sig. (2-tailed) N	-.138 422 36	1 0.63 36	-.313 0.063 36	-.057* 0.740 36	.093 0.591 36	.093 0.588 36	.159 0.354 36	-.235 0.247 12	-.021 0.948 36	-.172 0.105 36	-.172 0.317 36	-.065 0.708 36	-.037 0.831 36	-.450* 0.024 25	-.729* 0.005 13	-.120 0.485 36	-.092 0.592 36	.176 0.304 36	.041 0.813 36	
Q3 'Open Window' gave me a sense of connection with the outside world	Pearson Correlation Sig. (2-tailed) N	.613* 0.000 36	-.313 0.063 36	1 0.262 36	-.192 0.111 36	.417* 0.011 36	.324 0.054 36	.260 0.126 36	.117 0.571 26	.154 0.632 12	.404* 0.014 36	.545* 0.001 36	.297 0.079 36	.438* 0.008 36	.566* 0.003 25	.795* 0.001 13	.125 0.467 36	.171 0.318 36	-.555* 0.000 36	-.582 0.000 36	
Q4 'Open Window' was boring	Pearson Correlation Sig. (2-tailed) N	-.402* 0.015 36	-.057 0.740 36	-.192 0.262 36	1 0.006 36	-.453* 0.006 36	-.320 0.057 36	-.191 0.266 36	.124 0.545 26	.223 0.485 12	-.349* 0.037 36	-.207 0.227 36	-.177 0.302 36	-.318 0.059 36	-.218 0.296 25	-.318 0.290 13	-.024 0.892 36	-.030 0.863 36	.325 0.053 36	.032 0.853 36	
Q5 'Open Window' provided a soothing environment	Pearson Correlation Sig. (2-tailed) N	.536* 0.001 36	.093 0.591 36	.417* 0.011 36	-.453* 0.006 36	1 0.000 36	.776* 0.000 36	.382* 0.021 36	-.202 0.323 26	-.064 0.843 12	.236 0.166 36	.388* 0.019 36	.314 0.062 36	.366* 0.028 36	.149 0.478 25	.217 0.477 13	.171 0.318 36	.196 0.252 36	-.207 0.225 36	-.233 0.171 36	
Q6 'Open Window' was relaxing	Pearson Correlation Sig. (2-tailed) N	.558* 0.000 36	.093 0.588 36	.324 0.054 36	-.320 0.057 36	.776* 0.000 36	1 0.000 36	.601* 0.379 36	-.180 0.843 26	-.064 0.843 12	.263 0.122 36	.524* 0.001 36	.166 0.333 36	.422* 0.010 36	.106 0.614 25	.269 0.375 13	.345* 0.039 36	.377* 0.023 36	-.341* 0.042 36	-.098 0.570 36	
Q7 'Open Window' provided gentle stimulation	Pearson Correlation Sig. (2-tailed) N	.607* 0.000 36	.159 0.247 36	-.235 0.247 36	-.057* 0.740 36	.093 0.591 36	.093 0.588 36	1 0.354 36	-.235 0.247 12	-.021 0.948 36	-.172 0.105 36	-.172 0.317 36	-.065 0.708 36	-.037 0.831 36	-.450* 0.024 25	-.729* 0.005 13	-.120 0.485 36	-.092 0.592 36	.176 0.304 36	.041 0.813 36	
Q8 'Open Window' made me feel lonely when I saw familiar places	Pearson Correlation Sig. (2-tailed) N	.090 0.661 26	.263 0.410 12	.635* 0.000 36	.611* 0.000 36	.274 106 36	.367* 0.028 36	.344 0.092 25	.642* 0.018 25	.170 0.321 36	.226 0.185 36	-.598* 0.000 36	-.288 0.089 36								
Q9 'Open Window' made me feel lonely when I saw family images	Pearson Correlation Sig. (2-tailed) N	.263 0.410 12	.417* 0.011 36	-.453* 0.006 36	-.320 0.057 36	.776* 0.000 36	1 0.000 36	.601* 0.379 36	-.180 0.843 26	-.064 0.843 12	.263 0.122 36	.524* 0.001 36	.166 0.333 36	.422* 0.010 36	.106 0.614 25	.269 0.375 13	.345* 0.039 36	.377* 0.023 36	-.341* 0.042 36	-.098 0.570 36	
Q10 'Open Window' helped to reduce the boredom	Pearson Correlation Sig. (2-tailed) N	.635* 0.000 36	-.274 0.105 36	.404* 0.014 36	-.349* 0.037 36	.236 0.166 36	.263 0.122 36	.477* 0.003 36	.203 0.320 26	.131 0.685 12	1 0.685 36	.617* 0.000 36	.287 0.090 36	.341* 0.042 36	.386 0.057 25	.815* 0.001 13	.602* 0.000 36	.599* 0.000 36	-.530* 0.001 36	-.230 0.177 36	
Q11 The 'Open Window' images were enjoyable	Pearson Correlation Sig. (2-tailed) N	.611* 0.000 36	-.172 0.317 36	.545* 0.001 36	-.207 0.227 36	.388* 0.019 36	.524* 0.001 36	.558* 0.000 36	.302 0.134 26	.347 0.269 12	.347 0.269 12	.617* 0.000 36	1 0.308 36	.175 0.308 36	.589* 0.000 25	.539* 0.005 13	.870* 0.019 36	.390* 0.011 36	.417* 0.011 36	-.740* 0.000 36	
Q12 I preferred looking at the still images	Pearson Correlation Sig. (2-tailed) N	.274 106 36	-.065 0.708 36	.297 0.079 36	-.177 0.302 36	.314 0.062 36	.166 0.333 36	.133 0.438 26	-.164 0.423 12	-.384 0.218 36	.287 0.090 36	.175 0.308 36	1 0.308 36	-.108 0.529 25	.365 0.073 36	.489 0.385 13	.149 0.385 36	.133 0.439 36	-.261 0.124 36	-.271 0.110 36	
Q13 I preferred looking at the moving images	Pearson Correlation Sig. (2-tailed) N	.367* 0.028 36	-.037 0.831 36	.438* 0.008 36	-.318 0.059 36	.366* 0.028 36	.422* 0.010 36	.284 0.093 36	.078 0.706 26	.000 1.000 12	.341* 0.042 36	.589* 0.000 36	-.108 0.529 36	1 0.529 36	.344 0.092 25	.655* 0.015 13	.215 0.209 36	.269 0.112 36	-.465* 0.004 36	-.275 0.105 36	
Q14 I preferred looking at images of familiar places	Pearson Correlation Sig. (2-tailed) N	.344 0.092 25	-.450* 0.024 25	-.566* 0.003 25	-.218 0.296 25	.149 0.478 25	.106 0.614 25	.189 0.367 25	-.036 0.863 25	-.154 0.632 12	.386 0.057 25	.539* 0.005 25	.365 0.073 25	.344 0.092 25	1 0.000 25	.870* 0.000 13	.317 0.123 13	.334 0.103 13	-.614* 0.001 13	-.338 0.099 13	
Q15 I preferred looking at images of family	Pearson Correlation Sig. (2-tailed) N	.642* 0.018 13	-.729* 0.005 13	.795* 0.001 13	-.318 0.290 13	.217 0.477 13	.269 0.375 13	.533 0.061 13	.374 0.208 13	.125 0.713 11	.815* 0.001 13	.870* 0.000 13	.489 0.090 13	.655* 0.015 13	.870* 0.000 13	1 0.139 13	.433 0.139 13	.433 0.139 13	-.950* 0.000 13	-.462 0.112 13	
Q16 The music that accompanied the moving images was soothing	Pearson Correlation Sig. (2-tailed) N	.170 0.321 36	-.120 0.485 36	-.024 0.892 36	.171 0.318 36	.345* 0.039 36	.416* 0.012 36	-.114 0.579 26	-.170 0.598 12	-.390* 0.000 36	.602* 0.019 36	.390* 0.019 36	.149 0.385 36	.215 0.209 36	.317 0.123 25	.433 0.139 13	.1 0.000 36	.984* 0.000 36	-.182 0.287 36	.050 0.770 36	
Q17 The music that accompanied the moving images was relaxing	Pearson Correlation Sig. (2-tailed) N	.226 0.185 36	-.598* 0.000 36	.000 0.304 36	-.555* 0.003 36	-.325 0.053 36	-.207 0.225 36	-.341* 0.042 36	-.444* 0.164 26	-.281 0.632 12	-.154 0.632 36	-.599* 0.000 36	.417* 0.011 36	-.740* 0.000 36	-.950* 0.000 25	-.614* 0.001 13	-.950* 0.000 13	-.182 0.287 36	-.237 0.1 36	.438 0.008 36	
Q18 I did not like any of the images	Pearson Correlation Sig. (2-tailed) N	-.598* 0.000 36	.176 0.304 36	-.555* 0.003 36	-.325 0.053 36	-.207 0.225 36	-.341* 0.042 36	-.444* 0.164 26	-.281 0.632 12	-.154 0.632 36	-.599* 0.000 36	.417* 0.011 36	-.740* 0.000 36	-.950* 0.000 25	-.614* 0.001 13	-.950* 0.000 13	-.182 0.287 36	-.237 0.1 36	.438 0.008 36	1 0.008 36	
Q19 I preferred looking at TV	Pearson Correlation Sig. (2-tailed) N	-.288 0.089 36	.041 0.813 36	-.582* 0.000 36	-.233 0.171 36	-.233 0.171 36	-.098 0.570 36	-.189 0.271 26	-.004 0.984 26	-.156 0.628 12	-.230 0.177 36	-.310 0.066 36	-.271 0.110 36	-.275 0.099 36	-.338 0.112 25	-.462 0.070 13	.050 0.770 36	-.009 0.958 36	.438* 0.008 36	1 0.008 36	

\*\* . Correlation is significant at the 0.01 level (2-tailed).  
\* . Correlation is significant at the 0.05 level (2-tailed).

## **Appendix 9: Fieldwork**

## **Open Window Study Fieldwork**

### **Summary of main themes emerging from informal, unstructured interviews**

#### **Interview 1**

Felt like a prisoner – anxious, bored  
Felt depressed – not sure if this due to treatment or atmosphere – said atmosphere certainly didn't help  
Felt claustrophobic

#### **Interview 2**

Got used to it  
Prepared mentally prior to admission – did not feel anxious, bored or depressed.  
Has a calm demeanour anyway  
Did say that his environment made him feel sicker than he was

#### **Interview 3**

Felt bored, depressed and very 'down'  
Atmosphere adds to feelings of anxiety  
Feeling of no control  
Got irritated, snappy  
Got impatient, frustrated with illness and environment  
Tried to resign to situation

#### **Interview 4**

Lives alone so did not feel isolated in the room  
Enjoys reading, watching TV  
Daughter works in hospital so visited daily  
A bit bored initially but became resigned

#### **Interview 5**

Environment made it difficult to relax  
Wondered if the size of the window affected her mood  
Felt lonely and angry due to being separated from life  
Tried to become resigned to situation

#### **Interview 6**

Tried to use TV to reduce/prevent feelings of panic  
Being alone in room makes you depressed and dwell on things, then you become even more anxious  
Boredom made patient feel frustrated and angry – just wanted to leave

Would like pictures on the wall  
Tried to become resigned to situation

**Interview 7**

Felt lonely and socially isolated  
Felt depressed, frustrated, annoyed and had reduced tolerance  
Tried to become resigned to situation

**Interview 8**

Isolation was terrible  
Felt very cut off from people

**Interview 9**

Kept photos of family/friends/work in room – looking at them reduced loneliness and isolation  
Mum/friends visiting regularly helps a lot.  
Beginning to feel powerless  
Withdrew very quickly – no motivation  
Felt very insecure at thought of leaving hospital  
Feelings of loss of control mean that I am feeling anxious now

## **Appendix 10: Interview Guide**



## **Open Window Study**

### Interview Guide

#### **Control and Intervention Group**

Expectations  
Physical Environment  
Control  
Stress

#### **Intervention Group**

'Open Window'  
Likes/Dislikes  
How it made them feel

## **Appendix 11: Ethical Approval**

THIS DOCUMENT MUST NOT BE USED FOR  
PROMOTIONAL OR ADVERTISING PURPOSES

Dan Lynch, Secretary, SJH / AMNCH Research Ethics Committee  
Telephone: 4142869; Fax: 4142371; Email: dan.lynch@amrch.ie



**THE ADELAIDE & MEATH  
HOSPITAL, DUBLIN**  
INCORPORATING  
THE NATIONAL CHILDREN'S HOSPITAL

TALLAGHT, DUBLIN 24, IRELAND  
TELEPHONE: 4511 414,2000

Ms. Catherine McCabe,  
Research Fellow,  
Trinity College,  
School of Nursing and Midwifery,  
24 D'Olier Street,  
Dublin 2.

20th January, 2005

**Re: An evaluation of the effect of the 'Open Window' project on the sense of isolation while undergoing treatment for haematological malignancies in the Denis Burkitt Unit in St. James's Hospital.**

*Please quote this reference in all communications regarding this study: 0501/Chairman's Action*

Dear Ms. McCabe,

The Vice-Chairman of the SJH / AMNCH Research Ethics Committee has, on behalf of the Committee, given ethical approval for the above study.

Yours sincerely,

  
Daniel R. Lynch,  
Secretary,  
SJH / AMNCH Research Ethics Committee.



**Appendix 12: Permission from Patient Advocacy Committee**



## ST. JAMES'S HOSPITAL

James's Street, Dublin 8

Telephone (+353 1) 410 3000

[www.stjames.ie](http://www.stjames.ie)



Catherine McCabe,  
Research Assistant,  
St. James Hospital,  
Dublin 8.

2<sup>nd</sup> March, 2005

**RE: 'Open Window Study in the Denis Burkitt Unit'**

Dear Catherine,

Thank you for your amended copy of proposal to the Patient Advocacy Committee.

Further to our previous conversation, the Patient Advocacy Committee (PAC) reviewed your research proposal and I am delighted to inform you that approval has been given. I wish you every success with your research and if I can be of any help to you during this time please do not hesitate to contact me.

Yours sincerely,

**CAROL HICKEY**  
**QUALITY INITIATIVE OFFICER**



**Appendix 13: Trial Registry Form**



## Open Window Project

### Study Trial Register Part 1

Date  
Name  
Address  
Chart Number

### Part 2

#### Eligible for the 'Open Window' study

- Patients without communication difficulties, intellectual disabilities or known mental illness
- Undergoing an allogeneic or autologous stem cell transplant
- Can speak/read English reasonably well
- Agrees to participate
- Has not previously experienced 'Open Window'

### Part 3

Please indicate the type of transplant the patient is having by ticking the appropriate box.

Allogeneic stem cell transplant   
Autologous stem cell transplant

### Part 4

If the patient is not eligible to participate in the study please give reasons using the requirements listed in Part 2:

### Part 5

#### Consent

Consent form signed and witnessed Yes   
No

*If no, do not proceed to randomisation*

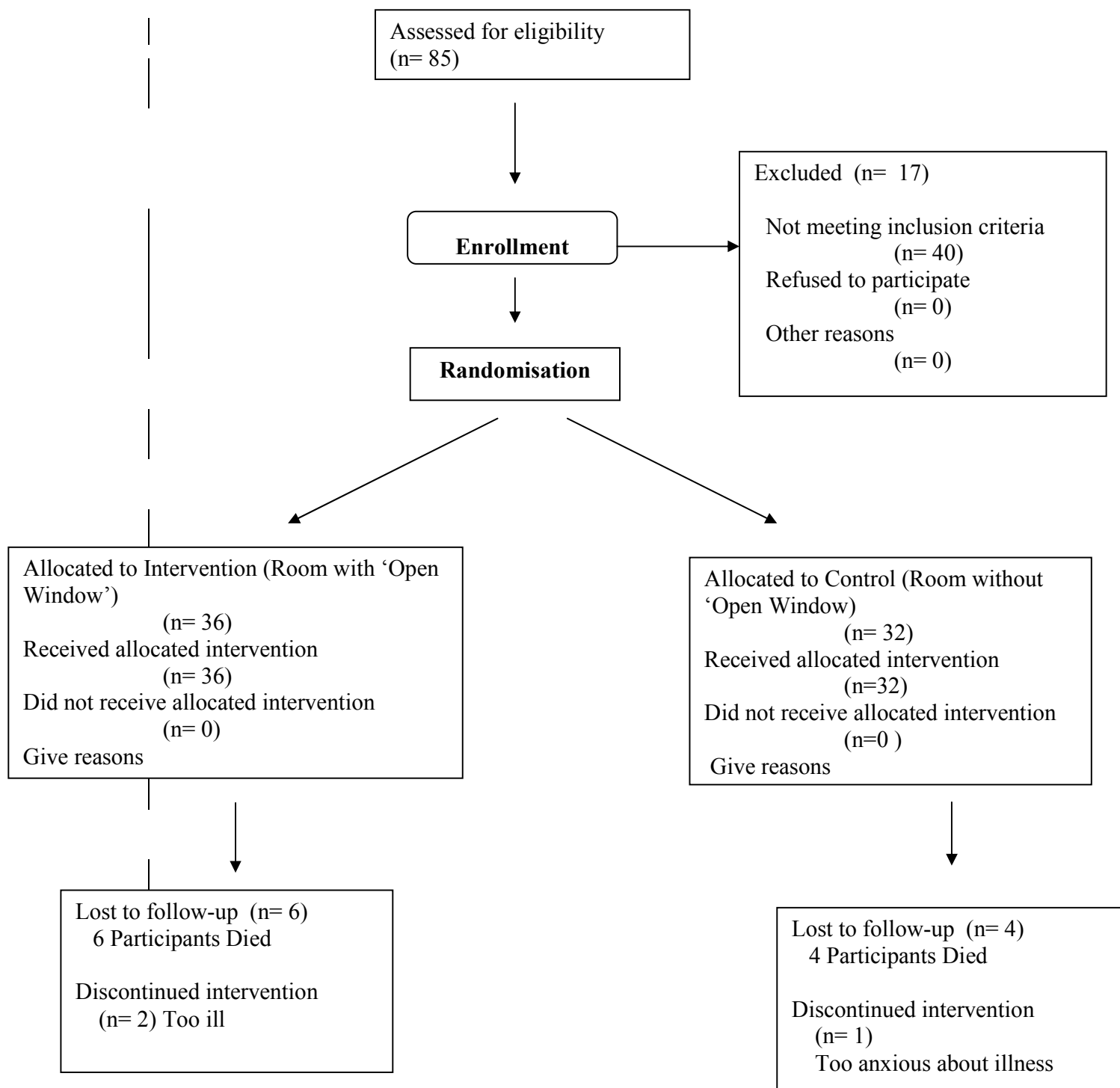
**Part 6**

<b>Randomisation</b>		
Allocation	Room with 'Open Window'	<input type="checkbox"/>
	Room without 'Open Window'	<input type="checkbox"/>

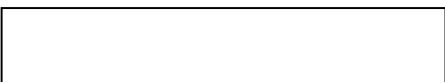
**Part 7**

<b>Participant Study Number</b>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
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## **Appendix 14: Flow Chart**



**Appendix 15: Patient Information Sheet**





**Who is running the study?**

Professor Straun MacCorm, Director  
Catherine McCabe, Research Assistant  
Doris Rodda, Admin/Curator  
Fran Hegarty, Project Manager

**Open Window Project**



Professor Cecily Bagley, School of Nursing and Midwifery, Trinity College, Dr. Sylvia Collier, Senior Clinical Psychologist with the Psycho-Oncology Team at St. James's Hospital, Maureen Cronin and Liz Higgins (Bone Marrow Transplant Co-Ordination), and the nursing staff and management in the Denis Burket are also involved in this study.

This study has received ethical approval from the St. James's Hospital and Trillick Hospital Joint Ethics Committee.

If you have any queries on the study, please contact me and I will gladly provide you with more information. My contact information is at the end of this leaflet.

**Who sees my medical information and is it kept private?**

I will be the only person collecting information from people taking part in the study and will store it in a secure place. I will need to see your medical records to collect information about your gender, date of birth and the family and social support that you have. I will code all this information, so it will not be linked to your name. As a result, nobody will be able to identify you.

**How do I join the study?**

You can join the study by filling in and signing both copies of the enclosed consent form. I will also sign both copies and keep one copy for my records and give the other copy to you.

**Where can I get more information?**

Please contact me with any questions.

Catherine McCabe  
Research Assistant  
Doris Burket Unit  
St. James's Hospital  
James's Street  
Dublin 8  
Tel: 006 8344 873, Email: c.mccabeb@tcd.ie

Thank you for your help



**Information leaflet**

**Open Window Project**



The 'Open Window' Study is a unique and novel project for patients being treated in the Denis Burket Unit. We would like you to take part in the study, which is looking at the effects of still and moving images on the psychological well being and overall experience while being treated in the Unit.

This leaflet contains more information about the study. Please read it carefully and feel free to ask any questions before deciding whether to take part.

**How does 'Open Window' work?**

'Open Window' shows still and moving images on the wall of your room. The images come from various artists, but if you wish the curator on the project can discuss the possibility of obtaining images from places that are familiar to you. Music may also be played as the images appear. 'Open Window' aims to:

- help patients deal with being in isolation;
- give patients a sense of connection with the outside world;
- provide patients with a relaxing and soothing environment while receiving treatment.

A trash set of images is shown every day and we study the effect of these before, during and after your treatment. Your involvement in the study, we hope, will help future patients being treated in the Denis Burket Unit.



## Open Window Project



### Can anybody get a room with 'Open Window'?

Only people who agree to take part in the study have a chance of getting a room with 'Open Window'. Also, because this is a research study, we are dividing people into two groups – those who get a room with 'Open Window' and those who do not. This helps us measure properly whether 'Open Window' has any effect on isolation, but means that you may not get a room with 'Open Window'.

If you get a room without 'Open Window' your care will be the same as it is for patients who decide not to take part in the study. However, the information you give us about your experience will still help us see if 'Open Window' is helpful for those who do have it. This will help us to provide better care for all patients in the future.

### What do I have to do as part of the study?

Information will be collected from you over a 6 month period (3rd estate or the day you come in to the Denis Burditt Unit and 5 months later. I will meet you on the following occasions to ask some questions and possibly interview you:

- on the day you are admitted to the Denis Burditt Unit
- on three other occasions during your time in the Unit; and
- on three occasions when you return to the hospital on follow-up visits, after you leave the Unit.

If you are given a room with 'Open Window', you will need to turn it on for at least 15 minutes every day. You can turn 'Open Window' on and off yourself, so often you have looked at it for 15 minutes, it is up to you how much you use it.



## Open Window Project



### What are the benefits of being in this study?

We hope that taking part in the study will benefit you in different ways.

- You may feel better when you look at images that are connected to the outside world.
- You might find the music feels more enjoyable than the images relating.
- The images and music may reduce your sense of isolation during your treatment.

### Are there any risks of being in this study?

We hope that the study will benefit you, but are aware that it may carry some risks.

- If you get a room with 'Open Window', you may find that a specific image is meaningful to you and upsetting.
- Whether or not you get a room with 'Open Window', you may become upset as you talk about your feelings and opinions during the interviews.

### What happens if I get upset while taking part in the study?

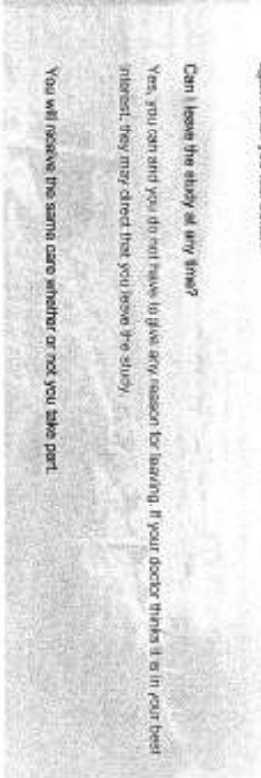
If an image is uncomfortable or distressing, you can turn it off and we will remove it if you like. The staff nurses and research assistant will talk to you about how the image made you feel and, if you like, the unit psychologist will also talk to you.

If you get upset during an interview, you may stop it altogether or stop for a short while and then start again when you feel better.

### Can I leave the study at any time?

Yes, you can and you do not have to give any reason for leaving. If your doctor thinks it is in your best interest, they may direct that you leave the study.

You will receive the same care whether or not you take part.



**Appendix 16: Consent Form**



### Consent Form

Please tick the correct boxes, 'Yes' or 'No', to confirm whether you understand and would like to take part in the study. When you have finished, make sure you fill in and sign both copies of the form.

I have also signed both copies. You will keep one copy and I will keep a copy for the study records.

Please tick 'Yes' or 'No' for each statement.

- |  | Yes                      | No                       |
|--|--------------------------|--------------------------|
| 1. I have read and I understand the information about the 'Open Window' Study.                               | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. I have had a chance to ask questions and discuss this study.  | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. I am satisfied with the answers to all my questions.  | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. I am fully informed of what the study involves for me.  | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. I agree to join the 'Open Window' Study.  | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. I understand that I can leave this study at any time and I do not have to give a reason.                  | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. I understand that the researcher will need to look at my medical notes and I give my permission for this. | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. I have signed two copies of this form and have kept one for myself.                                       | <input type="checkbox"/> | <input type="checkbox"/> |

Your signature: \_\_\_\_\_

Date: \_\_\_\_\_

Researcher's signature \_\_\_\_\_

Date: \_\_\_\_\_

Thank you for taking the time to fill in this form.

Catherine McCabe, Research Nurse, Denis Burkitt Unit, St James's Hospital

**Appendix 17: Telephone Randomisation Record**

Date	Caller	Consent	Allo	Study Number	Allocation	Hospital Number	Signature
26/7/06	Carolee	yes	✓	AI001	2	0535255	Caroline Byrne
16/8/06	"	"	✓	AI002	2	0504849	Caroline Byrne
30/8/06	"	"	✓	AI003	1	0537632	Caroline Byrne
"	"	"	✓	AI004	1	0537635	Caroline Byrne
7/9/06	"	"	✓	AI005	2	0538744	Caroline Byrne
"	"	"	✓	AI006	2	0538746	Caroline Byrne
"	"	"	✓	AI007	1	0521621	Caroline Byrne
1/9/06	"	"	✓	AI008	1	0531363	Caroline Byrne
16/10/06	"	"	✓	AI009	2	0536577	Caroline Byrne
26/10/06	"	"	✓	AI010	1	0563558	Caroline Byrne
6/11/06	"	"	✓	AI011	2	039732	Caroline Byrne
13/11/06	"	"	✓	AI012	1	042725	Caroline Byrne
"	"	"	✓	AI013	2	010074	Caroline Byrne
"	"	"	✓	AI014	1	036714	Caroline Byrne
20/11/06	"	"	✓	AI015	2	035448	Caroline Byrne
5/1/07	"	"	✓	AI016	1	785350	Caroline Byrne
"	"	"	✓	AI017	1	034302	Caroline Byrne
"	"	"	✓	AI018	2	040446	Caroline Byrne
15/1/07	"	"	✓	AI019	2	018603	Caroline Byrne
"	"	"	✓	AI020	2	053394	Caroline Byrne
10/2/07	"	"	✓	AI021	2	774718	Caroline Byrne
15/1/07	"	"	✓	AI022	1	034407	Caroline Byrne
15/1/07	"	"	✓	AI023	1	01019	Caroline Byrne
"	"	"	✓	AI024	1	045540	Caroline Byrne
20/1/07	"	"	✓	AI025	2	758601	Caroline Byrne
"	"	"	✓	AI026	1	047917	Caroline Byrne
5/2/07	"	"	✓	AI027	1	053660	Caroline Byrne
19/2/07	"	"	✓	AI028	2	051705	Caroline Byrne
11/3/07	"	"	✓	AI029	1	05720	Caroline Byrne
30/3/07	"	"	✓	AI030	2	04256	Caroline Byrne
"	"	"	✓	AI031	1	025157	Caroline Byrne
20/4/07	"	"	✓	AI032	1	051043	Caroline Byrne
20/4/07	"	"	✓	AI033	1	013962	Caroline Byrne
12/4/07	"	"	✓	AI034	2	050461	Caroline Byrne
17/4/07	"	"	✓	AI035	2	394201	Caroline Byrne
7/5/07	"	"	✓	AI036	2	062035	Caroline Byrne
20/5/07	"	"	✓	AI037	1	061282	Caroline Byrne
8/11/07	"	"	✓	AI038	1	059716	Caroline Byrne
20/5/07	"	"	✓	AI039	2	068712	Caroline Byrne
7/5/07	"	"	✓	AI040	2	043062	Caroline Byrne
14/5/07	"	"	✓	AI041	2	061928	Caroline Byrne

15/1/07  
"

7/6/07	✓	✓	✓	AI042	1	863476	Caroline Byrne
"	"	"	✓	AI043	2	857407	Caroline Byrne
15/6/07	"	"	✓	AI044	1	780526	Caroline Byrne
"	"	"	✓	AI045	2	630535	Caroline Byrne
"	"	"	✓	AI046	2	860707	Caroline Byrne
"	"	"	✓	AI047	1	657257	Caroline Byrne
2/7/07	"	"	✓	AI048	1	863876	Caroline Byrne
9/7/07	"	"	✓	AI049	2	844011	Caroline Byrne
16/7/07	"	"	✓	AI050	1	837631	Caroline Byrne
23/7/07	"	"	✓	AI051	1	851558	Caroline Byrne
27/7/07	"	"	✓	AI052	1	871451	Caroline Byrne
10/8/07	"	"	✓	AI053	2	871451	Caroline Byrne
16/7/07	"	"	✓	AI054	2	722115	Caroline Byrne
20/8/07	"	"	✓	AI055	1	871979	Caroline Byrne
27/8/07	"	"	✓	AI056	1	876482	Caroline Byrne
24/9/07	"	at	✓	AI057	2	875686	Caroline Byrne
13/10/07	"	"	✓	AI058	1	875816	Caroline Byrne
2/10/07	"	"	✓	AI059	1	625316	Caroline Byrne
11/10/07	"	"	✓	AI060	2	876266	Caroline Byrne
17/10/07	"	"	✓	AI061	2	876076	Caroline Byrne
11/3/07	"	"	✓	AI062	2	869425	Caroline Byrne
5/10/07	"	"	✓	AI063	2		
				AI064	1		
				AI065	1		
				AI066	2		
				AI067	1		
				AI068	2		
				AI069	1		
				AI070	2		
				AI071	2		
				AI072	1		
				AI073	2		
				AI074	1		
				AI075	1		
				AI076	2		
				AI077	2		
				AI078	1		
				AI079	1		

Date	Caller	Consent	Auto Set	Study Number	Allocation	Hospital Number	Signature
4/10/06	Carolee	yes	✓	Au001	1	0631445	Caroline Byrne
12/10/06	Carolee	"	✓	Au002	1	0827157	Caroline Byrne
2/10/06	"	"	✓	Au003	2	0657047	Caroline Byrne
"	"	"	✓	Au004	2	0201805	Caroline Byrne
"	"	"	✓	Au005	1	0617011	Caroline Byrne
5/10/06	"	"	✓	Au006	2	0632410	Caroline Byrne
7/10/06	"	"	✓	Au007	1	0636753	Caroline Byrne
"	"	"	✓	Au008	2	0631443	Caroline Byrne
"	"	"	✓	Au009	2	263274	Caroline Byrne
9/10/06	"	"	✓	Au010	2	834974	Caroline Byrne
"	"	"	✓	Au011	2	836755	Caroline Byrne
"	"	"	✓	Au012	1	465938	Caroline Byrne
22/10/06	"	"	✓	Au013	1	836755	Caroline Byrne
16/10/06	"	"	✓	Au015	1	841312	Caroline Byrne
23/10/06	"	"	✓	Au016	1	0445449	Caroline Byrne
6/11/06	"	"	✓	Au017	1	842669	Caroline Byrne
20/10/06	"	"	✓	Au018	2	731265	Caroline Byrne
4/11/06	"	"	✓	Au019	2	847494	Caroline Byrne
15/11/06	"	"	✓	Au020	2	847491	Caroline Byrne
"	"	"	✓	Au021	1	850825	Caroline Byrne
19/11/06	"	"	✓	Au022	1	717252	Caroline Byrne
4/12/06	"	"	✓	Au023	1	624682	Caroline Byrne
14/12/06	"	"	✓	Au024	2	872986	Caroline Byrne
14/12/06	"	"	✓	Au025	1	0630536	Caroline Byrne
2/1/07	"	"	✓	Au026	2	852440	Caroline Byrne
4/1/07	"	"	✓	Au027	2	753268	Caroline Byrne
9/1/07	"	"	✓	Au028	2	86550	Caroline Byrne
23/1/07	"	"	✓	Au029	2	870297	Caroline Byrne
2/2/07	"	"	✓	Au030	1	868055	Caroline Byrne
"	"	"	✓	Au031	1	702275	Caroline Byrne
4/2/07	"	"	✓	Au032	1	871823	Caroline Byrne
17/2/07	"	"	✓	Au033	1	363386	Caroline Byrne
20/2/07	"	"	✓	Au034	2	670600	Caroline Byrne
14/2/07	"	"	✓	Au035	2	840569	Caroline Byrne
16/2/07	"	"	✓	Au036	2	881242	Caroline Byrne
1/3/07	"	"	✓	Au037	2	882097	Caroline Byrne
7/3/07	"	"	✓	Au038	2	883785	Caroline Byrne
				Au039	1		
				Au040	1		
				Au041	2		
				Au042	1		



**Appendix 18: Transcript of Interview**

#### AI014IntT4

Q: The first thing I'd like to talk about are your expectations, about what you thought was going to happen to you when you're having a transplant, what it's been like?

A: Yeah it hasn't been as bad as I expected it like I would say you know the doctors give, build you up to all the problems that can occur you know and how sick you can get and that kind of stuff and I suppose mentally you try to tune in to that you're not going to get it, do you know that kind of way that you're going to stay strong and that kind of stuff but still subconsciously you're thinking 'hope I don't get' do you know so, but like they were saying I get really bad (inaudible) I didn't get it, you know that kind of way so.

Q: Alright yeah, yeah.

A: Eh after that then I was like I suppose I experienced really sick times in August and September or that kind of stuff.

Q: Yeah were there yeah.

A: Yeah I was bad then so the doctors had told that I wasn't gonna get any worse and I knew that mentally I kind of battled through that so I would have been, you know that kind of a way.

Q: Yeah so you've been through the worst already?

A: Yeah I've been through the worst.

Q: (Inaudible).

A: No, no.

Q: And the few times that you were sick here what was it like compared to August?

A: Eh I think there was a, I think they were better than August eh, August was I got one dose of chemo and then I was kind of, we say was flat you know as regards neutrophils and all that kind of stuff and, and I didn't get to recover or anything like that and then I went, was hit with a second dose and it was an intense enough dose so as a result then I was getting temperatures and you know.

Q: Alright.

A: The leukaemia hadn't been knocked off completely I wasn't in remission so, you know that was why I was probably so bad.

Q: But when you were physically low did that affect you psychologically?

A: Did it affect me psychologically; I don't think it did no like I was prepared for the bad days as in, I took it day by day you know that kind of a way.

Q: Mmm.

A: And like I wasn't worried about tomorrow and I worried about yesterday, yesterday was gone as far as I was concerned and then ok I was having a bad day and I was just dealing with that like and a lot of the time you're so zonked as in regards like, you know you get the riders (?) we'll say you get pethadine and you're just sleeping, you know that kind of a way?

Q: Yeah so time passes.

A: So time passes and the day just you know, you wake up the next day and hopefully it's a bit better and if it's a bit better then you say well yesterday is gone.

Q: Alright ok.

A: And that's the way I kind of dealt with it so I don't think you know, like I'm mentally fairly strong.

Q: Anyway?

A: Yeah.

Q: But what about the baby, you're expecting the baby, knowing that the baby was going to be born when you were here?

A: That was a big thing.

Q: Yeah how did you deal with that?

A: Yeah that was a big thing because eh, like you know you're worried about Mairead and you're worried that she's, you know going to be healthy she's going to be like, Mairead has a heart condition.

Q: Right.

A: So I was worried that you know everything was going to go ok for her and I was worried that the baby was going to be healthy and that kind of stuff and yet I was helpless do you know.

Q: Yeah I know yeah, yeah.

A: And I couldn't like you know get up and say 'listen I have to go and see Mairead I have to see if she ok' I basically you know was getting a text every so often saying 'she's grand' or which was difficult but I suppose I kind of, just had to, we'll say just think you know, she's, her sister and her mum were looking after her and like my brother and mum and dad were helping her as well anyway they could so she had good support in anywhere like she needed help like there was always help there and I just had to take it that you know and kind of prayed that everything was going to work out.

Q: Yeah.

A: And luckily and thank god like it kind of did you know that kind of a way.

Q: Yeah.

A: But I will say my, my body was all over the place the day that she went to hospital.

Q: Yeah, yeah.

A: You know I didn't know where my emotions were kind of messed up like I was you know was as a father and a child and I couldn't see it, I couldn't see my wife you know that kind of a way?

Q: Oh yeah, yeah.

A: And then I got sick we'd say the next day I got the shakes the next day and got a temperature and that kind of stuff so I was on (inaudible) for that day, the following day then I was kind of a bit weaker we'll say and then the baby arrived in and I just you know I didn't know where and I was exhausted as well you know so everything just piled in on top of me you know that kind of a way?

Q: Yeah.

A: And I suppose your body is an amazing thing in that I just, it just copes with it like you say like if someone had said to me and I often said this to you

previously if someone said to me you spend three months in a room, do you know where you're probably leave it two or three times I'd say, there's a not a hope in all of the world, do you know?

Q: Yeah, yeah, yeah (laughed).

A: And you just.

Q: And you did it.

A: I did yeah you just have to adapt to it you know that kind of a way.

Q: Looking back over the past few weeks especially around the time that Sinead was born do you remember it clearly, do you remember her coming in that day, is that a clear memory or is that?

A: Eh clear in ways and blurred in ways you know that kind of a way, section of it, I remember like picking off clearly and that kind of stuff and, do you know things like that but there is other things then that I you know I would say conversations that I don't remember kind of because I was probably so tired so drained emotionally you know that kind of a way I was just so relieved that everyone was ok do you know as well.

Q: Well looking back on it now even though I know you're not that far past it but looking back in the whole experience what are your feelings?

A: No I just delighted that everything turned out well you know that kind of a way, mummy's well, baby's well and you know I'm recovering as well so everything is going in the right direction and you know that kind of a way so like I think if I was maybe still sick I probably would look at it different but you know that kind of a way so eh, I don't know I think you know take the positives out of it you know.

Q: Yeah.

A: Everyone's healthy and that's the most important thing and.

Q: So on the whole in terms of your expectations it was better than you thought it was going to be?

A: Yeah it was better than I was going to thought, like a guy had said to me on the day ward one of the days that you know I said I was due in, I said I was

due in for a transplant and he said 'look it's not as bad as they make it out to be' and I kept that in my head kind of as well you know.

Q: Yeah ok so somebody else hadn't had an awful experience.

A: Yeah somebody that had been through it and Kathleen the nurse had said to me as well 'some people who are really sick initially you know in stage one and stage two of the treatment fly transplant'.

Q: Yeah.

A: So I kept them things kind of in my head so maybe I be one of them you know.

Q: Yeah everyone is so different you know.

A: Yeah.

Q: But I think you're probably right they give you the bad stories.

A: Yeah they have to you know?

Q: Yeah.

A: Eh so.

Q: Eh what about the room this room here, how would you describe it what words would you use now?

A: How would I describe it, genie eh like it's very plain you know what I mean it's clean its standard like you know it is immaculately clean.

Q: Yeah, yeah.

A: And but as regards you know it's just a very plain, kind of thing you know it's like four walls kind of two blue doors and that's it you know that kind of way.

Q: And the rest is white!

A: Yeah the rest is white and there's nothing really that stands out after that you know.

Q: Does it, does it affect you in any way do you have feelings about it?

A: I don't think so, no, like I just see it as a kind of a place that you have to be to get better.

Q: Yeah.

A: You know that kind of a way?

Q: Yeah.

A: And like obviously you love to be home do you know and you love getting home and home is obviously where the heart is you know that kind of a way so eh do I have feeling for it, probably not no like and hopefully when I get out of here I'll never see it again (laughed).

Q: Yeah see it sounds like you're talking about this as a functional place?

A: Yeah it's serving its purpose.

Q: Right there is a purpose.

A: Yeah.

Q: Ok so do you see as purpose then as being nearly medial like what, you're here and you're here for you transplant and the room allows you to have that transplant safe in?

A: Yeah completely yeah definitely and like totally happy as regards like the cleanliness and you know sometimes people give out about was, I was in hospital and you want to see, you know, like the place is spotlessly clean you know and.

Q: Yeah it is yeah.

A: Like it's cleaned in a regular basis and you know everything is sterilised and you know everyone is immaculate in regards to their, you know.

Q: Hygiene.

A: Hygiene yeah.

Q: And you feel that?

A: Yeah you do yeah.

Q: If there was something you could change about the room, anything what would it be or would it be anything?

A: I probably make the television, it's up high and it's small.

Q: Yeah.

A: You know that kind of a way?

Q: Yeah I do, I do.

A: And like you're lying in the bed and you're looking up at it the whole time.

Q: You're head is to the back.

A: Yeah whereas if it was on the wall there like you could actually look at it like that.

Q: If it was on eye level.

A: Yeah.

Q: You don't realise that you think that that would be an easy way to watch television it isn't.

A: Yeah but it's not no.

Q: Right ok.

A: So I suppose that's one thing I'd change you know.

Q: Yeah... anything else?

A: No anything else after that, eh like the chairs are great facility for people when they come in because they're so comfortable and like you can nearly sleep in them you know that kind of a way.

Q: Yeah they're great formulated.

A: Yeah it was brilliant formulated so that is a great facility to have like it nearly should be in every room I know there's only a couple of them but.

Q: Yeah they're comfortable actually.

A: Eh and it's just you know when people are visiting like especially when you have people that are regularly visiting and you know they're getting the trains up and you know it's a little bit of comfort when you arrive and that kind of stuff and even when I started getting better sometimes I sit out on it you know and it's nice and handy you can put, put it back there and fall asleep in it.

Q: I know because imagine if you were.

A: In that now the whole time.

Q: Yeah you know in this joke!

A: Yeah, yeah like it's not very cosy is it?

Q: No it's (inaudible) at your back.

A: Yeah as well yeah.

Q: But ok looking back again over the however many weeks you've been here, would you say that you had a sense of control over what's happened to you?



A: Had a sense of control, in many ways no.

Q: Alright.

A: And in some ways yes as regards like you know it's up to you to handle the whole thing you know that kind of a way.

Q: Yeah, yeah.

A: So you have to control it from your side of things and as well as that like you can always keep an eye on you know I'd always ask what drugs I'm getting and.

Q: Ok.

A: Why am I'm getting that or, do you know just to make sure you know you're aware of like, because sometimes the consultant might say to you 'oh I'm taking you off you know 'Tikoplane' or whatever it's called and the nurse might come in and say 'oh I'm gonna give you some' you say 'I think I'm off that' you know just, it just keeps you at bay kind of you know that you're confident and everything is well but like the nurses are brilliant that very seldom happens or anything you know so.

Q: Yeah but even as you say if it does happen you're in a position to say that and that's not a problem

A: Yeah, yeah.

Q: You feel very comfortable saying that.

A: Yeah, yeah.

Q: Oh that's good.

A: Do you know so and as well as that as regards like if anyone was doing your lining dressing and you weren't happy with it like you can turn around and say 'look I don't think you should be doing it that way' you know and I think that's important to be able to say that.

Q: Yeah.

A: You know.

Q: Eh even when you didn't have a sense of control or have, have you always felt you had a sense of control?

A: I think I have yeah.

Q: Do you mean what I mean.

A: Yeah I think I have.

Q: Is it something in your conscious of?

A: Ah I would be yeah.

Q: Would you?

A: Yeah I think I would I be kind of, as in kind of in what way you want to put it eh, yeah I suppose I'm just conscious of the fact that I want (inaudible) you know that kind of a way?

Q: Yeah, yeah of course.

A: Eh that I want to kind of keeping, you know I don't want everything going in and just to be completely oblivious to what, what you know like I'd like to know you know about certain things and what their for and that you know so.

Q: And as time goes on you know and you're recovering do you feel that you want more of that control is that something that?

A: It's yeah it's just you know like I'd like to know we'd say when you're getting Mexim you know it's for your stomach and when you get Encyclocene it's for anti sickness and you know just you know, so you'd why am I'm taking this tablet I'm just taking it for the sake of taking it and then I suppose subconsciously if you don't know what you're taking it for you probably start not taking it you know that kind of a way, you're ah sure I don't need that or.

Q: Right ok.

A: You know.

Q: Alright because I suppose for somebody in your situation compliance of medications.

A: Isn't it a huge thing yeah.

Q: But it sounds like just listening to you when you talk about control over your life you're life is centered on the drugs that you're taking.

A: Yeah well for the moment anyway.

Q: Yeah.

A: Yeah.

Q: Now as you moving on this continue do you feel though that there are other things starting to come in on that line you know it was you and your medication and your treatment and, you're, are you looking to the future now more?

A: It's just when you're on the road to recovery you just need to find out these things but when you get home you know why you're taking the tablets, you know what they're for so you just take them automatically.

Q: Right.

A: You get up in the morning you have to take x amount of tablets and that's what you do and you take them and that's it they're forgotten about.

Q: Ok.

A: Do you know that kind of a way.

Q: So there's no longer the focus?

A: No, no, no, no it's just on, when you're on the road for recovery I think.

Q: Alright ok.

A: And it was the same the last time I went home I used to say 'you know what do I need this for and what do I need that for' and then I would say I get up in the morning and I'd say 'ok I have to take Valtrax and Mexium and Zaptrum' and I know what they were for and I knew I needed to take them every day and that was it.

Q: Ok and that helped you do that?

A: Yeah do you know.

Q: Yeah, since you've been here have you experienced stress?

A: I suppose the day Mairead went in to labour in here that day was stressful.

Q: Right.

A: But up until that I don't think so no or like Mairead is a very level headed person and she's from a nursing background and she's been there the whole time so like when the doctors come in something that I didn't understand I'll just ask Mairead and she'll explained why it was or, you know or if the consultant didn't explain it himself you know that kind of a way.

Q: Yeah so information helped you deal with stress?

A: Information yeah, yeah.

Q: Mm and Mairead.

A: Yeah and Mairead so I think that's actually an important thing as regards like you know sometimes you might overhear the consultant say something outside the door or something and you say 'Jesus I wonder if they talk about me' do you know.

Q: Yeah, yeah.

A: That person has a temperature of forty like and they can go in to respiratory failure and then you say 'Jesus do you know I hope that wasn't' you know or whatever so things like that you know and then it could play in your head or whatever you know.

Q: Yeah of course you'd be thinking 'why didn't they tell me'.

A: Yeah 'why didn't they tell me' or whatever and then you know so I think it's important to ask questions you know as well so but I think that night now I didn't sleep well I didn't you know, I took two sleeping tablets I woke up an hour later so like normally the sleeping tablets knocked me out kind of for a couple of hours at least and I just you know I was worried that Mairead was ok, the baby was going to be ok and the next day I was kind of shattered from it all and I ended up getting the temperature and.

Q: Oh is there anything you could do when you were stressed, anything, nothing relieve that stress is it or?

A: Nothing really of that because it was a process that I had no access to no control over you know I wasn't able to, you know to do anything basically only like and at times I was actually on Saturday you know I was so unwell I didn't even text I couldn't even you know, I wasn't even in the humour of ringing kind of you know.

Q: And you (inaudible).

A: Yeah, yeah I was just sick in the bed and I was just thinking 'oh god I hope she's ok I hope the baby's going to be ok' you know so.

Q: And that was all you could do.

A: And that was all I could do so then, then the two days were stressful and the day, well say the baby arrived was stressful in that I didn't know what to think, I didn't know whether to laugh whether to cry whether to you know and that kind of stuff and then you know with the new baby it's so tiny and you know, you can't just pick it up and say you know have a chat with that kind of.

Q: Yeah, yeah it doesn't do anything.

A: No.

Q: Only lies there.

A: Yeah exactly so I will say them days were stressful in that aspect of things but not as regards you know anything else as regards my transplant or as regards my medication it was just a process that I had to go through.

Q: You said earlier before we started the interview that you were selective in terms of who your visitors are.

A: Yeah.

Q: Eh and that seems to be your brother, your parents and Mairead and that.

A: Yeah.

Q: Are they the people that you, you get support from in your life normally?

A: Yeah.

Q: Alright.

A: Yeah definitely yeah I have some great friends as well but I just couldn't, couldn't single out friends to come in that were in different scenarios and like I'm always been close to my family and obviously you know I married Mairead for a reason so Mairead has always been there for me as long as I was going out with her and so you know and that they've been brilliant like Mairead is just, like she's the softest character you could meet but she's just a complete rock for the last seven months, six or seven months you know, for a person you know that's so soft I can't believe how strong she's actually been.

Q: She'd been.

A: Yeah like she has so much excuse to complain we'll say as regards being pregnant as regards having a heart condition and never once did she turn around and said 'listen you know I have to start thinking of me' right up till the final day

that she was having her contractions in here like that she was putting it down to constipation like you know and it's amazing you know really when you think about that.

Q: Yeah so has this affected your relationship?

A: Eh has it affected our relations, it's probably made is stronger if that's possible.

Q: Yeah.

A: If, if it was possible you know to make it stronger it probably brought us that bit closer.

Q: You certainly learned things about her that you probably wouldn't have?

A: Yeah like I would have said that if we had a you know, if something was to happen in our lives that I would have been the stronger one but like I actually think and I think I'm a really strong person mentally but I actually don't think if it had been roles reversed that you know.

Q: Yeah, yeah, yeah.

A: But again your body is adjusting to it too you know?

Q: Yeah people do adjust (inaudible).

A: Yeah exactly.

Q: And your brother and your parents and that those relationships are as strong as ever?

A: Yeah, yeah.

Q: Ok eh, have you learned anything new about yourself?

A: Have I learned anything new about myself... I don't know I suppose how strong your character is you just learn how strong it actually is you know eh, how positive you are, you know you find out how positive you are and you know how, how you actually cope as a patient which I was never used to like you know I learned how I cope as a patient which I was never a patient previously I was never sick you know that kind of a way.

Q: Yeah, yeah, yeah.

A: And I went from being like a completely thirty one year old playing football on Saturday to a leukaemia patient on Wednesday you know that kind of a way.

Q: Complete on its head.

A: Complete on its head do you know and life just went from one extreme to the other as regards, you know so I suppose I learned that you know I learned that the importance of all my friends I've learned you know the importance of my family, not that I need you know, I learned even that they're even more important than I actually thought.

Q: Yeah just really (inaudible) really.

A: Yeah, yeah (phone rang). I ring you back right.

Q: It was Mairead?

A: Yeah.

Q: Oh I won't talk to you much longer.

A: No you're grand (phone rang).

Q: The next thing I want to talk to you about is open window.

A: Yeah.

Q: Would you be able to describe your experience with open window?

A: I thought the whole thing as regards getting the pictures was just amazing do you know what I mean because it was my contact to the outside world as regards like an event that was happening that I could never access so it was just unbelievable to be able to turn on the, a screen on the wall and see you know my wife, my new child, like I've seen my baby on a wall before I've actually seen her you know that kind of a way.

Q: Yeah, yeah, yeah.

A: And it was through modern technology I suppose if you want to put it down to that.

Q: Absolutely yeah, yeah.

A: Eh so like that experience was just priceless I suppose, eh I suppose to open windows itself I think maybe if it related more to things that you could relate to yourself.

Q: Yeah.

A: I think you get more out of it, eh like it is nice to look at you know and see nature and the cows and things like that but I think if we'll say the pictures were something you know good memories you had of you know maybe as a child or the road home or do you know that kind of a way?

Q: Absolutely yeah.

A: If you had a picture of the road home you could turn it on every day and say well there's where I want to be in three months time do you know that kind of a way, that's my goal.

Q: It's a goal or a purpose.

A: Yeah eh, whereas I think like looking at you know the river it's lovely to look at the river and the sun you know coming and the reflections and that kind of stuff and the sound but mentally I don't think I achieved anything from it.

Q: Yeah.

A: Do you know that kind of a way?

Q: Oh absolutely yeah.

A: Even though whereas if it had been the road home I could have always looked up and said 'well'...

Q: There it is.

A: Yeah that's what I want to be on.

Q: Yeah just to remind yourself.

A: Yeah or do you know it had to be a picture of your family and a happy day or, do you know or a group of your friends and a night out or, do you know things like that where you'd say 'well there be more of that in days ahead' do you know.

Q: Yeah and even if it's, it's yours it's your image that's up there you know as you said it connects you with what your life.

A: It connects you with yeah, yeah whereas you know the baby pictures were just priceless and that so but I do think it's a great facility but I think that if they relate it more to the patient I think could be, to the patients surroundings it might be better, and I don't know whether that's feasible to you know obviously start



handing out cameras here and there you know that kind of way I don't know if that's feasible but.

Q: No I think the intention is that it would be you know.

A: Yeah so maybe.

Q: Yeah.

A: Like different patients, some patients might say that they you know get great access of it so I'm just speaking personally.

Q: Yeah.

A: You know I'm not saying that that's the way it should be done eh, I'm just speaking from what I would.

Q: Yeah see as (inaudible).

A: Yeah.

Q: Did you have a preference for the type of images that you did look at like the moving images or the still images or

A: Eh I suppose like the fact that I'm from a farmer background it's always nice to look at the cows and kind of and, do you know that kind of a way and eh, the river was, the one with the bush probably didn't stand out that much you know it was it looked like a tree that was after being on fire kind of, do you know that kind of a way and you just look at it and go.

Q: Right.

A: You know, right yeah, switch that I think, do you know that kind of a way so.

Q: Yeah (laughed) there's one patient and he spent a long time looking at how he did it, he said he didn't like the picture but he was just wondering how he did it.

A: Yeah, yeah so like I'm sure, yeah there's the patient you know so whatever but, eh I don't know.

Q: What about the still images?

A: The still images? No I don't think like that has much out of the still images as...

Q: As the moving?

A: No as the moving no.

Q: Did open window how did it make you feel at any one time if you looked at something in particular that you liked even (inaudible) effected you.

A: Yeah completely it was great to just look at, it was amazing to look at and say that like I would never been able to access it only for that.

Q: Yeah.

A: Do you know so like them feelings I suppose like I suppose their personal feelings to me because it was my child or our child that was on the screen so when you look at it that way eh, it was probably just a mad feeling do you know that kind of a way?

Q: Yeah are you still getting new images in?

A: Yeah.

Q: Yeah eh, so we know looking at Sinead that would have effected you but just say some of the moving images that you may have liked do you think that they would have effected your mode or, or anything about you at any time?

A: Eh I suppose they maybe mellow you out a bit and kind of you know.

Q: Is that something you are conscious of though?

A: Is it something I was conscious of, eh I don't know, I don't know whether I'd say, I can't say I turned it on and you know that I was conscious that you know but.

Q: Like you didn't turn it on to become mellow?

A: No, no you know that kind of a way?

Q: Yeah, yeah.

A: But I turned it on and when you, you know I suppose it is actually an easing you know that kind of a way when you watching it.

Q: Ok and did you find yourself watching it or did you just turn it on and go about your business?

A: Oh no I turned it on yeah I turned it on and then but see a lot of times I flicked down to Sinead and kind of and, you know as well so, whether I turned it on and watched it specifically for you know actually sat down and watch it like a program I don't, I wouldn't say.

Q: Yeah, no that wouldn't be a like that anyway, yeah.

A: No, no I wouldn't say I've done that bit I definitely flicked.

Q: Yeah.

A: Yeah.

Q: Which is fair enough, eh do you have any comments about, well I think you probably made them all really.

A: Yeah I think that yeah as I said that the fact that if you could relate it to more to the person I think that would be a huge thing.

Q: Ok, is there anything else you would like to say that I haven't asked you about?

A: No that's it I think.

Q: Thanks, I'll turn this off now.

End of interview

**Appendix 19: 1st Phase of Analysis- Initial Template**

Appendix 16  
1st Phase of Analysis- Initial Template

Free Nodes

The screenshot shows the NVivo software interface. The 'Nodes' pane on the left is expanded to show 'Free Nodes'. The main window displays a table of search results for 'Free Nodes'.

Name	Sources	References	Created	Modified
Control Issues	151	156	29/03/2007 13:18	12/05/2008 13:37
Environment	152	155	29/03/2007 13:18	12/05/2008 13:37
Expectations	151	162	29/03/2007 13:10	12/05/2008 13:37
Open Window	51	53	04/04/2007 11:11	12/05/2008 13:37
Self and Others	137	160	18/04/2007 12:34	12/05/2008 13:37
Stress	151	154	29/03/2007 13:19	12/05/2008 13:37

## **Appendix 20: Sub themes – Tree Nodes**

## Appendix 17

### Sub themes – Tree Nodes

33 Tree Nodes / Sub themes emerged

The screenshot displays the NVivo software interface. On the left, a 'Nodes' pane shows a tree structure with 'Tree Nodes' selected. The main window shows a table of 33 tree nodes. The table has columns for 'Name', 'Sources', 'References', 'Created', and 'Modified'. An arrow points from the text '33 Tree Nodes / Sub themes emerged' to the top of the table.

Name	Sources	References	Created	Modified
Communication Issues	31	38	25/04/2	12/05/2008 13:36
Dealing with Stress	122	154	04/05/2	12/05/2008 13:37
Experiencing Stress	142	161	04/05/2	12/05/2008 13:37
General Perception of their Environment	91	129	23/04/2	12/05/2008 13:37
How Control Issues made Participants Feel	70	74	25/04/2	12/05/2008 13:37
How not having control made participants feel	58	68	25/04/2	12/05/2008 13:36
How 'Open Window' made me feel	34	86	05/05/2	05/05/2008 18:43
How 'Open Window' made the participants feel	31	49	27/05/2	12/05/2008 13:36
How Participants Retain a Sense of Control	55	73	25/04/2	12/05/2008 13:36
How the environment made the participants feel	114	148	23/04/2	12/05/2008 13:36
I have control over my life	48	90	30/04/2	12/05/2008 13:37
I have no control	48	48	30/04/2	12/05/2008 13:36
I have some control	43	45	25/04/2	12/05/2008 13:36
If I could change the room, I would ...	91	97	23/04/2	12/05/2008 13:36
Learning anything about themselves	79	97	01/05/2	12/05/2008 13:36
Life Altering Experience	27	29	04/05/2	12/05/2008 13:36
Life and Recovery after leaving Bukitt	44	104	04/01/2	12/05/2008 13:37
Likes and Dislikes about 'Open Window'	28	35	27/05/2	12/05/2008 13:36
Living through the Transplant Experience	38	96	19/04/2	12/05/2008 13:36
Long term effect of 'Open Window'	11	16	18/01/2	12/05/2008 13:36
Long term views of 'Open Window'	10	12	18/01/2	12/05/2008 13:37
Negative feelings about the room	38	53	26/05/2	26/05/2008 16:04
Opinions on 'Open Window'	18	24	18/01/2	12/05/2008 13:36
Perceptions of 'Open Window'	36	52	25/04/2	12/05/2008 13:37
Perceptions of the environment after the transplant	46	54	04/01/2	12/05/2008 13:37

**Appendix 20a. Sub themes – Tree Nodes continued**



## Sub themes – Tree Nodes

33 Tree Nodes / Sub themes emerged

The screenshot displays the NVivo software interface. The 'Nodes' pane on the left shows a tree structure with 'Tree Nodes' selected. The main window displays a table of tree nodes with the following data:

Name	Source	References	Created	Modified
Personality	13	15	04/05	12/05/2008 13:36
Phase 2 Analysis - Grouping	0	0	30/04	30/04/2008 12:07
Phase 3 Analysis - Hierarchy in Groups	0	0	07/05	07/05/2008 14:34
Phase 4 - Perspectives	0	0	04/05	04/05/2008 10:20
Physical Expectations	95	113	19/04	18/08/2008 17:17
Positive feelings about the room	22	28	26/06	26/06/2008 15:43
Psychological Expectations	105	190	19/04	18/08/2008 17:17
Relationship with Family and Friends	105	137	04/05	12/05/2008 13:37
Sources of support	52	64	04/05	12/05/2008 13:37
Tree nodes formed from phase 2 and 3 analysis	0	0	25/06	25/06/2008 16:25
Trust	7	8	25/04	12/05/2008 13:36
Words used to describe their environment	68	77	25/04	12/05/2008 13:36

**Appendix 21: 2nd Phase Analysis, Grouping with final template**

**2<sup>nd</sup> Phase of Analysis**  
**Grouping sub – themes with final template**

1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> Main Themes with Sub them

The screenshot shows the NVivo interface with a tree view of nodes. The nodes are organized into three main categories: Control Issues, Environment, and Expectations. Each category has several sub-nodes with associated source and reference counts.

Node Name	Source	Reference	Created	Modified
Phase 2 Analysis - Planning	0	0	30/04/2008 12:07	30/04/2008 12:07
Control Issues	145	190	30/04/2008 12:0	12/05/2008 13:37
Communication Issues	31	38	05/05/2008 11:17	12/05/2008 13:36
How Control Issues made Participants Feel	70	74	05/05/2008 11:14	12/05/2008 13:37
How not having control made participants feel	58	68	05/05/2008 11:14	12/05/2008 13:36
How Participants Retain a Sense of Control	55	73	05/05/2008 11:15	12/05/2008 13:36
I have control over my life	48	50	05/05/2008 11:16	12/05/2008 13:37
I have no control	48	48	05/05/2008 11:16	12/05/2008 13:36
I have some control	43	45	05/05/2008 11:16	12/05/2008 13:36
Trust	7	8	05/05/2008 11:17	12/05/2008 13:36
Environment	145	190	30/04/2008 12:0	12/05/2008 13:37
General Perception of the Environment	91	129	05/05/2008 11:11	12/05/2008 13:37
How the environment made the participants feel	114	148	05/05/2008 11:11	12/05/2008 13:36
If I could change the room, I would...	91	97	05/05/2008 11:12	12/05/2008 13:36
Living through the Transplant Experience	38	56	05/05/2008 11:27	12/05/2008 13:36
Perceptions of the environment after the transplant	46	54	05/05/2008 11:12	12/05/2008 13:37
Words used to describe their environment	69	77	05/05/2008 11:12	12/05/2008 13:36
Expectations	145	196	30/04/2008 12:0	12/05/2008 13:37
Life Altering Experience	27	28	05/05/2008 11:07	12/05/2008 13:36
Life and Recovery after leaving Buxtons	44	104	05/05/2008 11:07	12/05/2008 13:37
My Future	120	147	05/05/2008 11:06	12/05/2008 13:37
Physical Expectations	95	113	05/05/2008 11:00	18/08/2008 17:44
Psychological Expectations	105	180	05/05/2008 11:05	18/08/2008 17:44

**Appendix 21a: 2nd Phase of Analysis continued**

2nd Phase of Analysis  
 Grouping sub – themes with final  
 template continued

4<sup>th</sup>, 5<sup>th</sup> and 6<sup>th</sup> Main themes with sub themes

The screenshot shows the NVivo software interface with a tree of nodes. The nodes are organized into a hierarchy. The main themes are 'Open Window', 'Self and Other', and 'Stress'. Each main theme has several sub-themes. The table below represents the data shown in the screenshot.

Node Name	Source	Reference	Created	Modified
None				
Psychological Expectations	105	190	05/05/2008 11:05	18/08/2008 17:44
Open Window	90	52	30/04/2008 12:0	12/05/2008 13:37
How 'Open Window' made the participants feel	31	48	05/05/2008 11:18	12/05/2008 13:36
Likes and Dislikes about 'Open Window'	28	35	05/05/2008 11:19	12/05/2008 13:36
Long term effect of 'Open Window'	11	16	05/05/2008 11:19	12/05/2008 13:36
Long term views of 'Open Window'	10	12	05/05/2008 11:19	12/05/2008 13:37
Opinions on 'Open Window'	18	24	05/05/2008 11:19	12/05/2008 13:35
Perceptions of 'Open Window'	61	108	05/05/2008 11:19	12/05/2008 13:37
Too Sick to be interested in anything	18	21	05/05/2008 11:21	12/05/2008 13:36
Self and Other	131	154	30/04/2008 12:0	12/05/2008 13:37
Learning anything about themselves	79	97	05/05/2008 11:23	12/05/2008 13:36
Personality	13	15	05/05/2008 11:38	12/05/2008 13:36
Relationship with Family and Friends	105	137	05/05/2008 11:22	12/05/2008 13:37
Sources of support	52	64	05/05/2008 11:24	12/05/2008 13:37
Stress	145	148	30/04/2008 12:0	12/05/2008 13:37
Dealing with Stress	122	154	05/05/2008 11:24	12/05/2008 13:37
Experiencing Stress	142	161	05/05/2008 11:24	12/05/2008 13:37
Personality	13	15	05/05/2008 11:25	12/05/2008 13:36
Sources of support	52	64	05/05/2008 11:26	12/05/2008 13:37
Phase 3 Analysis - Hierarchy in Groups	0	0	07/05	07/05/2008 14:34
Phase 4 - Perspectives	0	0	04/06	04/06/2008 10:20
Physical Expectations	95	113	18/04	18/08/2008 17:17
Positive feelings about the topic	22	28	26/06	26/06/2008 15:43

**Appendix 22a: 3rd Phase Analysis Grouping/Hierarchy-Control**

### 3<sup>rd</sup> Phase of Analysis – Grouping and Hierarchy

Control Issues

The screenshot displays the NVivo software interface with a tree view of nodes. The tree is organized as follows:

- Phase 3 Analysis - Hierarchy in Group
  - Control Issues (145) (Source: 190) (Created: 07/05/2008 14:3, Modified: 12/05/2008 13:37)
    - I have control over my life (48) (Source: 50) (Created: 07/05/2008 14:35, Modified: 12/05/2008 13:36)
      - Communication Issues (31) (Source: 39) (Created: 07/05/2008 15:01, Modified: 25/06/2008 19:32)
        - Trust (7) (Source: 8) (Created: 07/05/2008 15:01, Modified: 12/05/2008 13:36)
      - How Participants Retain a Sense of Control (55) (Source: 73) (Created: 07/05/2008 14:40, Modified: 12/05/2008 13:36)
    - I have no control (48) (Source: 48) (Created: 07/05/2008 14:35, Modified: 12/05/2008 13:36)
      - Communication Issues (29) (Source: 29) (Created: 07/05/2008 15:01, Modified: 25/06/2008 19:32)
        - Negative Communication (13) (Source: 16) (Created: 25/06/2008 17:48, Modified: 25/06/2008 19:32)
        - Trust (7) (Source: 8) (Created: 07/05/2008 15:01, Modified: 12/05/2008 13:36)
      - How not having control made participants feel (58) (Source: 68) (Created: 07/05/2008 14:40, Modified: 12/05/2008 13:36)
        - I didn't mind not having control (14) (Source: 18) (Created: 24/06/2008 12:17, Modified: 07/07/2008 11:55)
    - I have some control (43) (Source: 45) (Created: 07/05/2008 14:35, Modified: 12/05/2008 13:36)
      - Communication Issues (31) (Source: 38) (Created: 07/05/2008 15:01, Modified: 12/05/2008 13:36)
        - Trust (7) (Source: 8) (Created: 07/05/2008 15:01, Modified: 12/05/2008 13:36)
      - Doctors will come back (13) (Source: 17) (Created: 03/07/2008 18:28, Modified: 03/07/2008 18:28)
      - How Control Issues made Participants Feel (70) (Source: 74) (Created: 07/05/2008 14:46, Modified: 12/05/2008 13:36)
  - Environment (146) (Source: 190) (Created: 07/05/2008 14:3, Modified: 12/05/2008 13:37)
  - Expectations (145) (Source: 196) (Created: 07/05/2008 14:3, Modified: 12/05/2008 13:37)
  - 'Open Window' (50) (Source: 53) (Created: 07/05/2008 14:3, Modified: 23/06/2008 14:04)

**Appendix 22b Environment**



Environment

The screenshot shows the NVivo software interface for a study named 'Open Window'. The main window displays a tree of nodes. The 'Environment' node is highlighted, and an arrow points from the word 'Environment' above to it. The tree structure is as follows:

- Control Issues (145)
- Environment (146)
  - General Perception of their Environment (91)
    - If I could change the room, I would ... (91)
      - Aesthetics of the room (52)
      - Practical issues about the room (35)
    - Words used to describe their environment (69)
  - How the environment inside the participants feel (114)
    - Prison (65)
      - Allogeneic Control (18)
      - Allogeneic Intervention (21)
      - Autologous Control (10)
      - Autologous Intervention (21)
    - The room made me feel safe (31)
  - Living through the Transplant Experience (38)
  - Perceptions of the environment after the transplant (45)
    - Negative Memories (29)
    - Positive Memories (27)
- Expectations (145)
- 'Open Window' (50)
- Self and Others (131)
- Control Issues (145)

Node	Count	Source	References	Created	Modified
Control Issues	145	190		07/05/2008 14:3	12/05/2008 13:37
Environment	146	190		07/05/2008 14:3	12/05/2008 13:37
General Perception of their Environment	91	129		07/05/2008 14:36	12/05/2008 13:37
If I could change the room, I would ...	91	97		07/05/2008 14:48	12/05/2008
Aesthetics of the room	52	55		04/06/2008 15:04	04/06/2008 15:04
Practical issues about the room	35	51		04/06/2008 14:59	04/06/2008 14:59
Words used to describe their environment	69	77		07/05/2008 14:47	12/05/2008
How the environment inside the participants feel	114	148		07/05/2008 14:36	12/05/2008 13:36
Prison	65	141		27/06/2008 13:58	27/06/2008
Allogeneic Control	18	44		27/06/2008 13:58	27/06/2008 13:58
Allogeneic Intervention	21	46		27/06/2008 13:58	27/06/2008 13:58
Autologous Control	10	24		27/06/2008 13:59	27/06/2008 13:59
Autologous Intervention	21	46		27/06/2008 13:58	27/06/2008 13:58
The room made me feel safe	31	49		27/06/2008 13:58	27/06/2008
Living through the Transplant Experience	38	56		07/05/2008 14:36	12/05/2008 13:36
Perceptions of the environment after the transplant	45	54		07/05/2008 14:36	12/05/2008 13:37
Negative Memories	29	36		04/06/2008 15:09	04/06/2008
Positive Memories	27	48		04/06/2008 15:23	04/06/2008
Expectations	145	198		07/05/2008 14:3	12/05/2008 13:37
'Open Window'	50	53		07/05/2008 14:3	23/06/2008 14:04
Self and Others	131	154		07/05/2008 14:3	12/05/2008 13:37
Control Issues	145	148		07/05/2008 14:3	12/05/2008 13:37

## **Appendix 22c: Expectations**

Expectations

The screenshot shows the NVivo software interface with a tree of nodes. The 'Expectations' node is highlighted, and an arrow points from the word 'Expectations' above to it. The tree structure is as follows:

- Free Nodes
  - Tree Nodes
    - Control Issues (145)
    - Environment (145)
    - Expectations (145)
      - Life Altering Experience
        - Different Priorities and Inner Strength (44)
      - Life and Recovery after leaving Bukitts (44)
        - I walk and do household chores and the garden (13)
        - I'm back diving now (8)
        - My normal life (15)
      - My Future (120)
      - Normal Life (48)
      - Physical Expectations (95)
        - Side Effects of medication (14)
      - Psychological Expectations (105)
        - Positive thinking (28)
    - 'Open Window' (50)
    - Sail and Others (131)
    - Stress (145)

Name	Source	References	Created	Modified
Control Issues	145	150	07/05/2008 14:3	12/05/2008 13:37
Environment	145	150	07/05/2008 14:3	12/05/2008 13:37
Expectations	145	158	07/05/2008 14:3	12/05/2008 13:37
Life Altering Experience	28	31	07/05/2008 14:37	02/07/2008 12:00
Different Priorities and Inner Strength	44	93	02/07/2008 14:53	02/07/2008 12:00
Life and Recovery after leaving Bukitts	44	104	07/05/2008 14:37	12/05/2008 13:37
I walk and do household chores and the garden	13	16	24/06/2008 16:24	24/06/2008 16:24
I'm back diving now	8	15	24/06/2008 16:24	24/06/2008 16:24
My normal life	15	22	24/06/2008 16:24	27/06/2008 16:24
My Future	120	148	07/05/2008 14:37	30/05/2008 19:43
Normal Life	48	99	24/06/2008 12:48	24/06/2008 12:48
Physical Expectations	95	113	07/05/2008 14:36	10/08/2008 11:50
Side Effects of medication	14	18	08/07/2008 11:42	08/07/2008 11:42
Psychological Expectations	105	180	07/05/2008 14:37	10/08/2008 11:50
Positive thinking	28	36	04/06/2008 16:22	04/06/2008 16:22
'Open Window'	50	93	07/05/2008 14:3	23/06/2008 14:04
Sail and Others	131	154	07/05/2008 14:3	12/05/2008 13:37
Stress	145	148	07/05/2008 14:3	12/05/2008 13:37
Phase 4 - Perspective	0	0	04/06	04/06/2008 10:20
Physical Expectations	95	113	19/04	18/08/2008 17:17
Positive feelings about the room	22	28	26/08	26/08/2008 15:43

**Appendix 22d: 'Open Window'**

'Open Window'

The screenshot shows the NVivo software interface with a tree of nodes. The 'Open Window' node is highlighted, and an arrow points from the text 'Open Window' to it. The tree structure is as follows:

- Phase 3 Analysis - Hierarchy in Groups
  - Control Issues (Sources: 145, References: 150)
  - Environment (Sources: 146, References: 150)
  - Expectations (Sources: 145, References: 156)
  - Open Window (Sources: 90, References: 53)
    - Long term effect of 'Open Window' (Sources: 11, References: 13)
      - 'Open Window' has a long term effect (Sources: 6, References: 7)
    - Long term views of 'Open Window' (Sources: 10, References: 12)
    - Opinions on 'Open Window' (Sources: 18, References: 24)
    - Perceptions of 'Open Window' (Sources: 61, References: 108)
      - Appreciation of Art (Sources: 29, References: 41)
      - How 'Open Window' made the participants feel (Sources: 31, References: 49)
        - 'Open Window' and connection (Sources: 30, References: 54)
        - 'Open Window' as a distraction (Sources: 31, References: 56)
      - Too Sick to be interested in anything (Sources: 19, References: 22)
  - Sell and Others (Sources: 131, References: 154)
  - Stove (Sources: 140, References: 148)
- Phase 4 - Perspectives (Sources: 0, References: 0)
  - Control Issues (Sources: 151, References: 156)
  - Environment (Sources: 152, References: 155)
  - Prison (Sources: 65, References: 141)
  - Physical Wellbeing (Sources: 96, References: 112)

**Appendix 22e: Self and Others**

Self and Others

The screenshot displays a software window titled "Open Window Study.msp - NVivo" with a menu bar (File, Edit, View, Project, Tools, Window, Help) and a toolbar. The main area is divided into a left sidebar and a central table.

**Left Sidebar:** Contains a "Nodes" section with a tree view including "Free Nodes", "Tree Nodes", "Cases", "Relationships", "Matrices", "SearchFolder", and "AllNodes". Below this are buttons for "Sources", "Nodes", "Sets", "Queries", "Models", "Links", "Classification...", and "Folders".

**Tree Nodes Table:**

Name	Sources	References	Create	Modified
Phase 3 Analysis - Hierarchy in Groups	0	0	07/05/2008 14:34	07/05/2008 14:34
Control Issues	146	150	07/05/2008 14:35	12/05/2008 13:37
Environment	146	150	07/05/2008 14:36	12/05/2008 13:37
Expectations	146	156	07/05/2008 14:36	12/05/2008 13:37
Open Window	80	53	07/05/2008 14:37	23/05/2008 14:04
Self and Others	131	154	07/05/2008 14:38	12/05/2008 13:37
Learning anything about themselves	79	97	07/05/2008 14:38	12/05/2008 13:36
Different Practices and Inner Strength	44	53	02/07/2008 14:52	02/07/2008
Personality	13	15	07/05/2008 14:53	12/05/2008
Relationship with Family and Friends	105	137	07/05/2008 14:38	12/05/2008 13:37
Sources of support	52	64	07/05/2008 14:38	12/05/2008 13:37
Shame	146	148	07/05/2008 14:38	12/05/2008 13:37
Phase 4 - Perspectives	0	0	04/06/2008 10:20	04/06/2008 10:20
Control Issues	151	156	04/06/2008 10:22	04/06/2008 10:22
Environment	152	155	04/06/2008 10:46	04/06/2008 10:46
Prison	85	141	04/06/2008 11:13	26/06/2008 19:14
Physical Wellbeing		95	113	19/04/12/05/2008 13:36
Positive feelings about the team		22	26	26/06/26/05/2008 15:43
Psychological Wellbeing		105	180	19/04/12/05/2008 13:36
Relationship with Family and Friends		105	137	04/05/12/05/2008 13:37
Sources of support		52	64	04/05/12/05/2008 13:37
Tree nodes formed from phase 2 and 3 analysis	0	0	25/06/25/06/2008 16:25	25/06/25/06/2008 16:25
Total				26/06/26/06/2008 13:36

At the bottom, the Windows taskbar shows the Start button and open applications: "Open Window Study...", "Microsoft Word", and "Microsoft PowerPoint". The system tray on the right shows the time as 09:00 and the date as 12/05/2008.

## **Appendix 22f: Stress**



Stress

The screenshot displays the NVivo software interface with a tree view of nodes. The 'Stress' node is highlighted, and an arrow points to it from the word 'Stress' written above the window. The tree structure is as follows:

- Phase 3 Analysis - Hierarchy in Groups
  - Control Issues
  - Environment
  - Expectations
  - Open Windows
  - Sell and Offers
  - Stress
- Dealing with Stress
  - Personality
  - Sources of support
    - Family and friends were a source of support
    - Prayer was a source of support
    - TV and reading were a source of support
- Experiencing Stress
  - Communication Issues
    - Trust
      - I have experienced stress
      - I have not experienced stress
- Phase 4 - Perspective
  - Control Issues
  - Environment
  - Prison

184 items

### **Appendix 23: Memos for phase 2, 3 and 4 Analysis**

**Memo's written for each parent, child, grandchild and great grandchild in Phase 3 Analysis are colour coded for clarity. They consist of an executive statement for the parent nodes/themes and a summary statement for each nodes/sub-themes**

- **Parent nodes/themes**
  
- **Children nodes/sub-themes**
  
- **Grandchildren nodes/sub-themes**
  
- **Great Grandchildren nodes/sub-themes**

### **Phase 2 Analysis – Grouping**

This phase of the analysis was straight forward; it involved grouping all tree nodes (sub themes) under the relevant free node (main theme). Some nodes, for example, communication, was relevant to a number of nodes, therefore can be found listed in more than one group. Memos for each group will be included at phase three analysis as this will provide a more comprehensive and cohesive picture of the outcome of the analysis.

### **Phase 3 Analysis – Hierarchy in Groups**

This phase of analysis is the most detailed and presents the tree nodes in hierarchical format and includes new grandchildren and great grandchildren not seen in phase 2 analysis. The level of analysis seen here reflects the descriptive design of the qualitative aspect of this study. Although these data emerged from semi structured interviews I was cogniscent of the purpose of choosing to conduct this embedded qual-quant mixed methods design study. However, I also explored and reflected on the data to identify any new or unexpected ideas or information that might emerge.

### **Control Issues**

Participants were asked if they perceived that they had control over their lives or situation. Some said yes, some said no and others said they believed that they had some control. Responses to how they felt about control varied with some having a more positive outlook than others. All participants looked forward to recovering and regaining control over day-to-day living.

#### **I have Control over my life**

Participants who perceived that they had control over their lives were quite emphatic about this. They were confident that they continued to make decisions and be part of activity related to their treatment, daily life in the Denis Burkitt Unit and plans for their discharge and recovery. This perception of control centered on seeking and being given appropriate information by relevant people but also tended to related to how these participants perceived themselves and their personalities. In other words, if they always had control in their lives, there is no need to give it up now!

#### **Effect of communication on participants' sense of control**

Most participants described their relationship with staff in positive terms. Staff were helpful, kind, informative etc. Some however commented specifically on how different types of communication affected them.

#### **Trust in Health Care Professionals**

Some participants described trusting the staff (i.e. all staff) of the Denis Burkitt Unit in a way that suggested it was essential in giving the participants confidence in the treatment and recovery process. This appeared to contribute their perception of whether they had any control over their situation. Trusting the staff meant that even if they perceived that they didn't have control, it did not cause negative feelings, they trusted others to have control. This node is linked with communication node because it is feasible to suggest that poor or negative communication as an adverse effect on establishing a trusting

relationship. In any relationship with patients, it is the onus of the health care professional to realise the importance of and develop a trusting relationship in order to provide therapeutic care.

#### **How participants retained a sense of control**

When asked if they felt they had control over their lives, some participants commented that they had control, whereas others said they had some control. Retaining control centered on keeping informed of the treatment and recovery process. This meant persistently asking questions of the medical/nursing staff and believing that the responses they received were informed and genuine. This relates back to the communication skills of the health care staff and their ability to establish a trusting relationship with participants. Other participants felt that they retained control by having a positive mental attitude and complying fully with treatment even though they did not always understand the purpose of the medication they were on. Participants also felt a sense of control over the decision to have a transplant, ultimately they felt that this had been their decision and therefore were prepared for the consequences and the importance of complying with treatment. The need to be in the right place in order to recover was evident as a way of retaining some sense of control. Having a daily routine in hospital and control over activities such as music, reading and TV were also perceived as important in that they could control that.

#### **I have no control**

Some participants who felt that they did not have any control did not regard this in negative terms because they did not expect to be able to control something they knew nothing about or did not understand and appeared to accept that. They were happy to leave this to the doctors and nurses who were professionals. This implies underlying trust in their professional ability. Other participants described feelings of frustration and talked about their desire to regain control as they recovered and got back to their 'normal' lives.

#### **How communication issues adversely affected participants' sense of control**

Although participants did not generally refer directly to communication issues, some comments suggested that negative or poor interpersonal relationships with health care staff had an adverse affect on their sense of control. This was linked also with whether they trusted the staff in providing meeting their needs in terms on information and care. If they did not trust the staff, this had a negative affect on how confident or in control they felt.

#### **The effect of negative communication on participants' sense of control**

Some participants who indicated that they did not believe they had any control over their lives commented on how negative communication made them lose confidence in their treatment and feel that they were not respected as individuals.

#### **Trust**

Although this did not happen often but when participants commented that they did not trust the health care staff, it seemed to reduce their confidence in terms of treatment and clearly made them feel more anxious. The lack of trust seemed to emanate from comparisons with the previous hospital staff where the participant was treated. They may have felt that interpersonal relations were better there or sometimes it stemmed from a negative communication experience they had in the Denis Burkitt Unit. Fundamentally, lack of trust was linked with poor communication.

### **Participants' feelings about not having control**

Participants generally felt frustrated about not having control and looked forward to when they would be able to live their 'normal' lives again. Some talked about feeling depressed about it and some suggested that not having control made them feel insignificant as an individual. They lost their 'role' in the family and could not contribute; they felt, in a meaningful way. However, most saw this as a temporary measure and looked forward positively to regaining control.

### **I don't mind not having control**

Some participants felt that although they didn't have control over their lives, it was a problem or negative experience. They were content to let those that they perceived to have the expertise make the decisions. This implied an underlying trust in the health care staff and their environment. They suggested that they were in the best place possible in order to have a chance of full recovery.

### **I have some control**

The perception of having control or not was not a yes or no answer for some participants. They felt that they had control in relation to other aspects of their lives, for example, their relationships with family and friends. Some felt that they had control over their daily routine and activities in the Denis Burkitt Unit but that when it came to administering, understanding and recovering from treatment, they no longer had control. This was not described as a problem but regarded as not their area of expertise. They also felt that they exerted control in complying with treatment and in even making the decision to have the transplant.

### **Communication affects sense of control**

Some participants commented on positive and negative communication experiences with the health care staff in the Denis Burkitt Unit. Good communication seemed to give the participants confidence and made them feel cared for as individuals whereas bad communication increased their feelings of anxiety and isolation. It appears that good communication helped participants retain feelings of control over their situation and negative communication makes them perceive their lack of control more negatively rather than view it in a positive light.

### **Trust affects sense of control**

Participants who perceived that they had some control over their lives but not generally in relation to their treatment tended to perceive this positively if they trusted the staff, in other words, not having control was ok because they were in safe hands. However, not trusting staff to do their job resulted in higher anxiety and a lack of confidence in their situation overall. Most participants did not comment on whether or not they trusted the staff and very few commented that they did not trust them.

### **The Cancer might come back**

Although most participants were optimistic about regaining control of their lives in stages as they recovered, some felt that regardless of how well they recovered or how normal their lives were, the possibility of the cancer returning would always be in their minds to a greater or lesser degree. They felt that this meant they would never have control of their lives in the same way they did before they became ill and some felt that it could impact on their daily lives because they would worry more if they were feeling unwell.

### **How control issues made the participants feel**

This node encompasses many views from participants who perceive that they have control over their lives to a greater or lesser degree. Feelings of frustration and sometimes anger are verbalised but this is generally accompanied by an understanding and acceptance that this is what they need to do in order to have a chance of being disease free and returning to normal life. Some participants became used to the feeling of others controlling their lives and this made the experience easier to accept but it took time.

### **Environment**

This node encompasses all comments that participants made in relation to their immediate surroundings and the wider environs of the Denis Burkitt Unit. Comments related to positive and negative views, how it made them feel and how they would change the environment if they could.

### **General perceptions of their environment**

When participants were asked for their views of the environment their responses generally related to practical or aesthetic issues. Some spoke positively, but many highlighted negative aspects of the room. These criticisms were underpinned by an understanding of its purpose, and function and an appreciation that it was a hospital room and not a hotel room. They talked about the effect the room had on them and how they would change the room if they could.

### **Descriptions of their environment**

Participants used words such as clinical, clean, functional, bright, airy and nice when providing positive descriptions. Words such as dark, small, and prison like were used in negative descriptions. Other terms included 'hospital like', grand were used when participants did not have particularly strong feelings about their environment one way or the other.

### **If I could change the room I would ...**

Participants were asked what aspects of their environment they would change if they had the choice. Practical issues such as the shower, TV, lack of storage space and size of the room were common and aesthetic issues such as the colour and decor of the room were identified at much the same frequency.

### **Aesthetics of the room**

Aesthetics of the room relates to participants comments on what they would change about the room if they could. They talked about changing the colour to something warmer or more homely. Some suggested hanging pictures or trying to improve the view through the window. The shape and size of the room was an issue for some patients and one commented on the 'plastic' feel to the room.

### **Practical issues about the room**

Participants commented on issues such as the lack of storage space, and no wardrobe for their personal things. The lack of furniture generally was commented on, particularly easy chairs for patients and visitors. The shower was also frequently mentioned as a source of inconvenience due to the lack of shower curtain and even danger in some cases. The TV was often described as being too small and far away. Food was mentioned although less frequently, as a source of distress. This was due to its odour

and lack of variety, participants did however, acknowledge that they were so ill, it would have been difficult to provide appetising food.

#### **How the environment made them feel**

Participants generally described the effect of their environment in positive or negative terms. They rarely commented that the room did not affect them except perhaps when they were at their sickest and were not particularly interested in anything. The environment generally made the participants feel safe or like they were in a prison and on occasion, participants described feeling like they were in prison but if given the choice they wouldn't leave because it was where they needed to be.

#### **It felt like prison**

Participants described the environment as prison like for a number of reasons. These included not being able to go outside for fresh air, the use of double doors and the ante chamber before entering the room, limited visitors. These issues resulted in feelings of confinement and isolation. Some descriptions were accompanied by comments indicating that participants also understood why they were there, the reasons for the restrictions and if given the choice would not want to be anywhere else because that is where they needed to be in order to get better. An exploration of the perspectives of the four different groups indicated very little difference between the autologous and allogeneic groups even though the latter spent a great deal longer in isolation.

#### **It made me feel safe**

The visiting restrictions, the cleaning regimen and the air lock were identified by participants as key factors in making them feel safe from infection. This gave them confidence in their overall treatment. This feeling of safety was common although not as common as the confined or prison like feeling.

#### **Life in the Denis Burkitt Unit**

This node refers to various descriptions of day-to-day life in the Denis Burkitt Unit provided by the participants. These descriptions do not relate specifically to any of the other themes but provide an insight into the intensity and side effects of treatment and living with this.

#### **Long term perceptions of the environment**

Participants were asked about their memories and feelings of their room and the Denis Burkitt Unit six months after the transplant. Many commented that they tried to forget about it and those that remembered it indicated that the source of the either positive or negative views were the same as when they were in patients. Some had visited the unit since being discharged, others felt they could not as it would upset them.

#### **Negative memories**

When participants were asked to think back to their room and the Denis Burkitt Unit, some verbalised negative memories. These centered mainly on similar aesthetic and practical issues they talked about during their admission. The confinement and isolation were also mentioned.

#### **Positive memories**

Positive memories related to feelings of safety, security and being in the right place in order to get better. Cleanliness, bright rooms and helpful supportive staff were



mentioned. The issues that were identified as positive by participants at the time of their transplant had not changed five months later.

### **Expectations**

Participants were asked specifically about their expectations of their physical and psychological response to treatment and recovery and their future. Other issues that emerged from this theme were the transplant as a life altering experience, and life and recovery in the six months after transplant.

### **Life altering experience**

Having a life threatening illness, being treated and recovering have the potential to be life altering events. Participants in this study commented that other than perhaps taking more holidays, spending more time with family, their main aim was to return to 'normal life'. The only sense in which this experience was life altering was in their self awareness and having a more 'easy going' approach to life.

### **How this experience changed me**

Participants in this study indicated that the only they felt they had changed or the experience had the potential to alter their lives was in two ways. The first was that they felt they prioritised differently as a result of their experience, things that would have bothered them in the past, what they referred to as 'minor things' would no longer affect them. It sometimes irritated them when they saw family/friends worrying over silly things. Even though they prioritised differently they generally did not feel different or distant from family/friends but just more aware. The second perhaps not so life changing but certainly an increase in self-awareness was their new found inner strength and self admiration for how well they dealt with their situation. This was often identified or highlighted by friends or family members.

### **Life and recovery after leaving the Denis Burkitt Unit**

This part of their experience related to treatment required and recovery after leaving the Denis Burkitt Unit. Participants talked about the difficulties and challenges related to this process. This centered on issues like intense fatigue and how this made traveling to the day centre very difficult and traumatic at times. Worry about the possibility and extent of GVHD, or acquiring infection were to the forefront of their minds. Participants who underwent autologous transplants did not have these concerns and tended to recover quicker, however, they also found it difficult to return to normal life due to fatigue. The common goals of recovery regardless of type of transplant were to return to normal life, this entailed driving, walking, or household chores.

### **Walking and household chores**

Walking and household chores seemed to be the most common goal in returning to normal life. Getting out for a walk, doing the garden or even just hanging out the washing represented important milestones. These activities in conjunction with reducing visits to the day ward and less medication were signs of recovery and progress.

### **I'm back driving now**

Although not many participants talked about being back driving, those that did suggested that it was a means of regaining independence and control over their lives. They didn't have to rely on anyone and could act independently on minor personal decisions.



### **Getting back to my normal life**

While many participants referred to specific aspects of their lives that were important to them, for example, driving, walking or household chores, some just talked about getting back to their old lives and working. The normality, familiarity and day-to-day nature of the activities they talked about did not require any life changing actions.

### **My future**

When participants talked about their future they were generally very optimistic but tended not to plan too far ahead. Their main expectation in relation to the future was to return to their normal lives. Some talked about returning to a different kind of work or job, others felt that they would limit the work they did or not return at all. The future consisted of more family or personal time, not so much rushing around. The future did not include any grand plans of dramatic changes in lifestyle. Recovery and return to normality was the predominant plan.

### **Back to my old normal life**

Returning to their old normal life was the aim of all the participants with some adjustments related to spending more time on themselves and doing what they wanted to do or perhaps relaxing more. They did not want to make any dramatic changes to their lives and expressed contentment at the lives they led before becoming ill. It seems that the future expected and hoped for by the participants was just every day life with family, friends and work colleagues.

### **Expectations about physical response to treatment and recovery**

Participants generally felt that they knew what to expect in relation to how they might respond physically to the treatment. Nausea, vomiting, fatigue and diarrhoea were top of the list but many also felt that they may not get these symptoms too badly and based this on their past experiences of chemotherapy. Some were confident that with medication they would be able to handle these symptoms. The symptom they were most wary of was mucocytis as this would set them back in their physical recovery. The high risk of infection was also on their minds but participants generally felt that if they stayed in their room and had limited visitors, they would be ok. There was a high level of confidence that the nursing and medical staff would be able to anticipate their needs or help them if they needed it. However, many participants commented that at times they were so ill that they had no concept of time or had no interest in anything. Many just pulled the blinds on the window and slept or lay in bed dozing. This time was usually from day 7 to day 15 or so.

### **The side effects of medication were difficult to deal with**

One aspect of their physical response to treatment was the unexpected and/or difficult side effects of medication. The drug most commonly mentioned was morphine which caused confusion, and hallucinations that patients found disturbing and were often surprised by how much this disturbed them. Some indicated that they would not wish to take it again and felt that if given the choice they would not have taken it if they had known the side effects.

### **Expectations about psychological response to treatment and recovery**

Participants were generally quite confident that they would be able to cope well psychologically with the intensity of the treatment and recovery. As with the physical

symptoms, this was based on their past experiences of being in hospital and being very ill for long periods of time. Others felt that positive thinking was a key factor and consciously tried to do this. They talked about the need to distract themselves by reading, watching TV or sleeping. Sleeping was valued as the best way to get through a difficult day of physical or psychological symptoms and it also passed the time. Most participants referred to the presence of immediate family as important to them even if they didn't interact a great deal with them. Contact with friends was minimal when participants were feeling down mentally or physically but receiving texts or cards was a significant source of support.

#### **Positive thinking**

Positive thinking was something that many participants talked about in relation to the psychological well being. They were conscious of its importance to their state of mind and tried to think and talk positively about their illness and life generally. During interviews with participants it was clear that they did not feel sorry for themselves and many talked about the positive impact that the illness had on certain aspects of their lives, for example, closer relationships with family and friends. Participants seemed very aware of the life threatening nature of their predicament and appeared to deal with this in a positive manner. Even in terms of getting through 'bad' days, they allowed themselves bad days and didn't seem to mind talking to people about how their feelings.

#### **Experience of 'Open Window'**

Participants were asked to describe their overall experience of 'Open Window' with particular reference to their likes, dislikes and how it made them feel. This did not seem to be a difficult request for them although some were apologetic because they said they were too ill to be interested in it or anything. Participants were happy to provide feedback and one participant kept a notebook on his experience.

#### **Perceptions of 'Open Window' in the Denis Burkitt Unit**

Participants experiences of 'Open Window' while in the Denis Burkitt Unit seemed to be two pronged. The first was their appreciation of art although they may not have been aware that this is what they were doing. The second was comments on how it made them feel which centered on distraction and connection with the outside world. Over time this extended to a limited long term effect but appreciation of art continued in participants contribution of their opinion and views of 'Open Window' even six months after their transplant. It is clear that from a subjective perspective the null hypothesis suggesting that 'Open Window' has no effect is rejected. Participants experience of 'Open Window' indicate that its value as an art work lies in its ability to distract and connect participants but also retain its integrity as a art that like any other type of art in any other context, compels people to respond!

#### **Participants' appreciation of art**

Participants were always very happy to comment on their likes and dislikes about 'Open Window', they talked about the importance of positive images, colour and life. When they didn't like something they were always very clear about why they didn't like it and often this was because they saw no meaning in it or it didn't relate to them in any way. Other reasons included the images being too dark or abstract. However, regardless of whether they liked it or not they spent time expressing their opinion. This is similar to practices in an art gallery or community art, it always draws a comment from the viewer

and demonstrates engagement or even aesthetic absorption. When recruiting participants for this study it was agreed not to use the word 'art' as this could alienate people who believe they know nothing about it and therefore feel that they cannot engage or respond to it. In hindsight this was probably the right thing to do as participants did not appear to be intimidated by 'Open Window' or the request to express their views and feelings on it.

#### **How 'Open Window' made the participants feel**

When asked how 'Open Window' made them feel some participants used the word 'distraction' or nice, interesting or something else to look at. Others used terms such as relaxing, reflect, "it was like I was there", or "took me away from here" or personal and exciting. It became clear that some participants regarded 'Open Window' as a distraction, others felt it provided connection with the outside world and some experienced the value of both effects.

#### **'Open Window' and connection**

Participants commented on how certain images on 'Open Window' helped them to relax or just reflect on life and their situation. Others felt that they could imagine being in the images that they viewed, they felt that the images allowed them to be somewhere else for a while other than their room and even think about something else other than their illness. Participants did not generally use the term 'connection' but they talked about the importance of finding personal meaning in the images they saw or imagine being somewhere else. Most participants chose to view personal images or images of familiar places but many found meaning in images that unrelated to them. They valued a connection between themselves and the image they looked at, for example, some of Suzanne Mooney's work reminded them of the Burren in Clare or the video piece of New York was particularly interesting to a patient who had plans to visit there when she recovered. She said she would look at it and wonder would she recognise places when she was there in reality. Those that looked at personal images were happy to see everyday things like the new car that they hadn't seen because they were in hospital or the dog. Some were pleased to see from the images that things had not changed much at home. Others were just excited to see what images their family thought they would like to see.

#### **'Open Window' and distraction**

Participants regularly used the word 'distraction' to describe their experience of 'Open Window'. It gave them something else to look at or do besides look at the blank wall or just lie there on the bed looking at TV. This is perhaps a useful effect because it might help participants pass the time more easily or just relieve the boredom. As a distraction it could also have the similar effect as connection in that it gives the participant a new experience and stops them thinking about their own situation for a period of time. Perhaps the difference between distraction and connection is the level of meaning perceived by the viewer to exist when they look at an image?

#### **Too sick to be interested in anything**

Participants often commented that due to their physical response to treatment, they were too sick to be interested in anything. This included interacting with staff or family, reading, watching TV or 'Open Window'. They apologised for this and said that they became interested again when they felt physically better.

### **Effect of 'Open Window' at six months after the transplant**

Participants generally felt that 'Open Window' did not have a long term effect. One of the reasons for this may be because they consciously tried not to think about their time in Burkitts and as they associated 'Open Window' with that time, it meant they also tried not to think about it. One participant commented that hearing a particular bird sound reminded her of Burkitts and in the early stages after her discharge, this had a negative impact on her. This negative effect did not last long and now she can think about 'Burkitts' and therefore, 'Open Window' without experiencing anxiety or a negative emotion. Two other participants talked about how they would choose a different location to have personal images sent in from now and had even thought about where they would like to see on 'Open Window' if given the choice again. Participants were able to recount their experience when asked to think about it and even had suggestions as to how it could be developed in the future. Overall participants commented positively on their experience.

### **Long term effect of 'Open Window' on Participants views of art**

Participants who described a long term effect of 'Open Window' referred to an increased awareness or interest in art. This was visual art and generally scenes of nature or scenes that reminded them of 'Open Window'. It seemed to be quite an understated effect but participants who experienced it still seemed to have strong memories of 'Open Window'.

### **Views about 'Open Window' six months after the transplant**

Although many participants' felt that 'Open Window' did not have a long term effect on their views or interest in art, many still had strong memories of what they liked about it and what they saw on it. Others talked about their lack of interest in it and why it wasn't really for them.

### **General opinion of 'Open Window'**

Some participants commented on the way they thought 'Open Window' should be developed and what content would be most appropriate. The most common opinion that offered was the importance of 'Open Window' to contain images that were relevant or familiar to the patients as other art, contemporary, classical or otherwise would not be of interest to people without knowledge of art.

### **Self and others**

Self and others was not one of the original topics included in the semi structured interview, it emerged as a new theme and formed one of the main themes on the final template. In this theme participants talked about the things they had learned about themselves as a result of going through the experience of being diagnosed with and receiving treatment for a life threatening illness. They also talked about how relationships with family and friends had changed during this time. This theme was somewhat of a surprise in that it was very positive, participants did not seem to feel sorry for themselves and at times talked about the positive or good things to come out of their illness and experience and they were happy about that.

### **Learning anything new about themselves**

Some participants felt that they had not learned anything about themselves or that they had not changed in any way and that their response to their experience reflected their

personality and the way they would always have dealt with things. Most, however, expressed the view that they had learned things about themselves and almost all said that they had changed in some way. Many said that they were psychologically, physically and emotionally than they thought they were but particularly psychologically and emotionally stronger. They felt that they had changed in that they prioritised differently, did not get as stressed about things and were able to relax more.

#### **I'm a stronger person than I thought and I prioritise differently now**

Participants expressed surprise at how much inner strength they had, this related to psychological and emotional strength particularly. They liked this and it may have contributed to their sense of control and also their confidence in thinking positively about their situation. Some participants said they learned about this from friends and family but many said they felt it themselves. It is clear that personal growth is a feature of this experience.

Many participants said that as a result of having a life threatening illness, they now prioritised things differently in their lives. They did not get as stressed, they did not get concerned, or irritated over what they perceived to be minor issues and at times felt irritated when friends and family seemed anxious over something trivial. When asked if they felt this alienated them from others or made them feel different in any way, the participants responded that it didn't or if it did, they felt it didn't affect their relationships with others.

#### **That's just the way I am**

Those participants that felt they had not changed in any way explained their response to having a life threatening illness and undergoing transplant as the same as they would normally have responded to any crisis in their lives. This was their personality that tended to reflect a pragmatic approach to life and difficulties/challenges.

#### **Relationship with family and friends**

The relationship that participants had with family was consistently reported as positive and a key source of strength and support. Many reported that their relationships had grown and become stronger and they commented on this very positive aspect of their difficult situation. The physical presence of family in their room was extremely important and contact by phone or email was also reassuring. Some participants felt that being diagnosed with a life threatening illness made them realise who their real friends were and expressed surprise that some friends were not as supportive as they thought they might have been. On the positive side they felt that many new friendships were formed so social relationships were also generally perceived positively. However, it was clear that close family relationships were the most important, supportive and reassuring, this included parents, children, brothers, and sisters and partners. Outside of this circle, relationships were important but not essential.

#### **Sources of support**

Family was identified as the main and most important source of support for the participants. This is where the close relationships were evident and participants sometimes became emotional when talking about them. They valued the way in which the family came together and coped at home and were a constant presence in hospital. They also seemed to learn the value of talking about the situation as a family and not

hiding things. Other sources of support included friends, and the medical/nursing staff in the Denis Burkitt Unit and the Day ward.

### **Stress**

Stress is a common cause of anxiety in people diagnosed with and undergoing treatment for cancer. In this study the participants were asked if they felt they experienced stress and how they dealt with it. They indicated that they either had or had not experienced stress and identified ways in which they addressed their stress.

### **Experiencing stress**

Participants talked about how they experienced stress by being angry, or more anxious. Some didn't feel that being stressed was a major problem and either dealt with it or ignored it. How they experienced it was influenced by their previous exposure and reactions to stress. Some commented that stress was never an issue, it didn't feature in their lives. It was clear that some were more aware of it than others and also people addressed it in varying ways. Even though the majority of participants in this study experienced stress it seemed to be acute episodic stress that was reduced when symptoms were relieved or they started responding to treatment with blood counts going up. Chronic stress was not described by any of the participants.

### **I have experienced stress**

There were almost 33% more reports of experiencing stress than those who said they did not. The main causes of stress were related to the side effects of treatment, such as appearance, or pain or diarrhoea. However the stress reported was low level, acute and/or episodic.

### **I have not experienced stress**

Participants who said they did not experience stress were quite emphatic about it. They said things had gone better than they expected or they didn't generally experience stress anyway in their lives. Most took the pragmatic approach to their situation and regarded it as something they had to do in order to get better. This psychological approach may have helped to reduce or limit levels of stress and it is evident from earlier themes (Psychological Well-Being) that this was important to patients and they seem well prepared.

### **The influence of communication on levels of stress**

Some participants commented on how negative interactions with health care staff made them upset and anxious or even stressed. This is similar to perceived control where negative interactions were also associated with reduced perceptions of control. The number of negative interactions reported was generally low, therefore it is safe to assume that it was not the main cause of stress. Acute physical symptoms were probably more stressful.

### **Trust and its influence on stress levels**

When participants talked about a lack of trust of the health care staff and the system in general, it appeared to cause increased anxiety and stress. As with negative communication, the number of participants that reported a lack of trust was low. However, it is clear that when it occurs it can increase levels of stress either directly or through a perceived lack of control as discussed in the earlier theme of 'Control'.

### **Dealing with stress**

Participants identified numerous ways in which they dealt with stress. These included medication, music, being irritable. Others distracted themselves by reading, writing or going on their computer. Many said they dealt with by just getting on with things and attributed this to their personality. Others used various support structures that they found helpful.

### **My personality helps me deal with stress**

A number of participants commented that the way they dealt with stress reflected their personality. They took a pragmatic approach and just got on with things or they did not think about it at all.

### **Sources of support in dealing with stress**

Most participants identified a number of support structures that they used to deal effectively with stress. They did not seem to need any new or specific interventions to help them deal with it and the three most common sources for helping them were family/friends, prayer and TV/reading. On the whole stress did not seem to be a major problem and tended to be acute and of short duration, that is, related to specific incidents such as side effects of medication.

### **Family and friends helped deal with stress**

Family and friends were the most common source of support in dealing with stress. They talked openly with family about their illness and side effects of medication. They obviously trusted family to understand when and why they did not want to talk at times and also know when they were ready and able to be more independent.

### **Prayer helped me deal with stress**

Although not many participants referred to prayer as important in any aspect of their treatment, those that did regarded it as the single most important support structure in dealing with stress.

### **Reading and TV helped deal with stress**

This was the least common way of dealing with stress with only 3 participants indicating they read or watched TV to deal with stress. This may be because as indicated in one of the earlier themes, extreme physical responses to treatment meant that participants had no interest in anything, therefore watching TV or reading would not have been the most appropriate choice for dealing with stress.

## **Phase 4 Analysis – an exploration of perspectives**

In this stage of the analysis, a small number of issues were explored to see the difference between the groups. What instigated this was my belief that participants in the allogeneic groups referred to the environment as 'prison' like more than the autologous groups. I also felt that due to the duration of their treatment and confinement in the unit, they would be more concerned about control. However, conducting these queries illustrated that this was not the case and although differences existed between the groups, they were small. The implications are that subjectively there is very little difference between the groups in relation to environment and control issues.

**Appendix 24: Phase Four Analysis – Perspectives**



Phase 4 Analysis - Perspectives

Control Environment Prison

The screenshot shows the 'Open Window' software interface with a 'Tree Nodes' table. The table lists various nodes and their associated source and reference counts. Three arrows point from the text 'Control Environment Prison' to the 'Control Issues', 'Environment', and 'Prison' nodes in the tree.

Node	Source	References	Created	Modified
None				
Open Window	50	53	07/05/2008 14:3	23/06/2008 14:04
Self and Others	131	154	07/05/2008 14:3	12/05/2008 13:37
Stress	145	148	07/05/2008 14:3	12/05/2008 13:37
Phase 4 - Perspectives	0	0	04/05	04/05/2008 10:20
Control Issues	151	198	04/05/2008 10:2	04/05/2008 10:22
Allogeic Control		41	04/05/2008 10:28	04/05/2008 10:28
Allogeic Intervention		44	04/05/2008 10:25	04/05/2008 10:25
Auto Control		29	04/05/2008 10:30	04/05/2008 10:30
Auto Intervention		36	04/05/2008 10:30	04/05/2008 10:30
Environment	152	195	04/05/2008 10:4	04/05/2008 10:45
Allogeic Control		41	04/05/2008 10:50	04/05/2008 10:50
Allogeic Intervention		45	04/05/2008 10:49	04/05/2008 10:49
Autologous Control		29	04/05/2008 10:51	04/05/2008 10:51
Autologous Intervention		36	04/05/2008 10:50	04/05/2008 10:50
Prison	65	141	04/05/2008 11:1	26/06/2008 19:14
Allogeic Control		18	04/05/2008 11:17	04/05/2008 11:17
Allogeic Intervention		21	04/05/2008 11:16	04/05/2008 11:16
Autologous Control		10	04/05/2008 11:18	04/05/2008 11:18
Autologous Intervention		21	04/05/2008 11:17	04/05/2008 11:17
Physical Expectations	95	113	19/04	18/03/2008 17:17
Positive feelings about the room	22	38	25/05	26/05/2008 15:43
Psychological Expectations	105	190	19/04	18/03/2008 17:17
Relationship with Environment	105	137	04/05	04/05/2008 10:20

**Appendix 25: Value of ‘Open Window’ for Participants**

## Value of 'Open Window' for Participants

Appreciation of Art    Connection    Distraction

Name	Sources	References	Create	Modified
Phase 3 Analysis - Hierarchy in Groups	0	0	07/05/2008 14:34	07/05/2008 14:34
Control Issues	146	150	07/05/2008 14:35	12/05/2008 13:37
Environment	146	150	07/05/2008 14:36	12/05/2008 13:37
Expectations	146	156	07/05/2008 14:36	12/05/2008 13:37
'Open Window'	50	53	07/05/2008 14:37	23/06/2008 14:04
Long term effect of 'Open Window'	11	13	07/05/2008 14:37	23/06/2008 14:04
'Open Window' has a long term effect	5	7	16/06/2008 13:37	17/06/2008 13:37
Long term views of 'Open Window'	10	12	07/05/2008 14:37	12/05/2008 13:37
Opinions on 'Open Window'	18	24	07/05/2008 14:37	12/05/2008 13:37
Perceptions of 'Open Window'	61	108	07/05/2008 14:37	12/05/2008 13:37
Appreciation of Art	29	41	07/05/2008 14:52	25/06/2008 13:37
How 'Open Window' made the participants feel	31	49	07/05/2008 15:00	12/05/2008 13:37
'Open Window' and connectivity	30	54	16/06/2008 13:38	08/07/2008 12:15
'Open Window' as a distraction	31	56	16/06/2008 13:38	08/07/2008 12:14
Too Sick to be interested in anything	19	22	08/07/2008 11:55	08/07/2008 11:55
Self and Others	131	154	07/05/2008 14:38	12/05/2008 13:37
Stress	145	148	07/05/2008 14:38	12/05/2008 13:37
Phase 4 - Perspectives	0	0	04/06/2008 10:20	04/06/2008 10:20
Control Issues	151	156	04/06/2008 10:22	04/06/2008 10:22
Environment	152	155	04/06/2008 10:46	04/06/2008 10:46
Prison	65	141	04/06/2008 11:13	26/06/2008 19:14
Physical Wellbeing	96	112	19/06/2008 13:36	12/05/2008 13:36

**Appendix 26: Long term effect of ‘Open Window’**

Long term effect of 'Open Window'

Increased awareness  
of nature and art

The screenshot shows the NVivo software interface with a tree node structure. The 'Open Window' node is expanded, showing several sub-nodes. An arrow points from the text 'Increased awareness of nature and art' to the node 'More aware of nature and art'.

Name	Sources	References	Created	Modified
Personally	13	15	04/05/2007 10:41	12/05/2008 13:36
Phase 2 Analysis - Grouping	0	0	30/04/2008 12:07	30/04/2008 12:07
Phase 3 Analysis - Hierarchy in Groups	0	0	07/05/2008 14:34	07/05/2008 14:34
Control Issues	145	190	07/05/2008 14:35	12/05/2008 13:37
Environment	145	190	07/05/2008 14:36	12/05/2008 13:37
Expectations	145	196	07/05/2008 14:36	12/05/2008 13:37
'Open Window'	90	93	07/05/2008 14:37	23/06/2008 14:04
Long term effect of 'Open Window'	11	13	07/05/2008 14:37	23/06/2008 14:21
More aware of nature and art	6	7	16/06/2008 19:37	23/06/2008 16:11
Long term views of 'Open Window'	10	12	07/05/2008 14:37	12/05/2008 13:37
Opinions on 'Open Window'	18	24	07/05/2008 14:37	12/05/2008 13:36
Perceptions of 'Open Window'	61	108	07/05/2008 14:37	12/05/2008 13:37
How 'Open Window' made the pa...	21	49	07/05/2008 15:02	12/05/2008 13:36
Likes and Dislikes about 'Open W...	28	35	07/05/2008 14:52	12/05/2008 13:36
'Open Window' and connection	29	53	16/06/2008 19:39	23/06/2008 15:21
'Open Window' as a distraction	31	55	16/06/2008 19:38	23/06/2008 15:20
Too Sick to be interested in anyth...	19	22	07/05/2008 14:52	23/06/2008 13:30
Self and Others	131	154	07/05/2008 14:39	12/05/2008 13:37
Stress	145	149	07/05/2008 14:39	12/05/2008 13:37
Phase 4 - Perspectives	0	0	04/06/2008 10:20	04/06/2008 10:20
Physical Wellbeing	90	113	19/04/2007 14:23	12/05/2008 13:36
Patience for Moving Images	11	11	17/06/2008 19:09	17/06/2008 19:11
Psychological Wellbeing	109	190	19/04/2007 14:27	12/05/2008 13:36

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