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Childhood Cancer In The Cinema: How The Celluloid Mirror Reflects Psychosocial Care

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CHILDHOOD CANCER IN THE CINEMA:
HOW THE CELLULOID MIRROR REFLECTS PSYCHOSOCIAL CARE

A Thesis Submitted to the
Yale University School of Medicine
In Partial Fulfillment of the Requirements for the
Degree of Doctor of Medicine

By
Jovana Pavisic
2013

ABSTRACT

CHILDHOOD CANCER IN THE CINEMA: HOW THE CELLULOID MIRROR REFLECTS

PSYCHOSOCIAL CARE. Jovana Pavisic^a, Julie Chilton^a, Garry Walter^b, Nerissa L. Soh^b, and Andrés S. Martin^a. ^aChild Study Center, Yale University School of Medicine, New Haven, CT. ^bThe University of Sydney Medical School, Sydney, Australia.

Film is a powerful medium for sharing illness narratives, and can exert a significant influence on public medical discourse. The childhood cancer narrative has more recently emerged on the screen, and these images have yet to be analyzed. This study aims to evaluate the childhood cancer experience in commercially produced, readily available films with a character with childhood cancer, with a particular focus on psychosocial care. Twenty-nine films were reviewed, using quantitative and qualitative content analysis to identify the medical and psychosocial characteristics of the cinematic childhood cancer experience. Psychosocial support was rated on a five-point scale (0-4) based on the availability and efficacy of support characters in the categories of non-professional internal (e.g. parent), non-professional external (e.g. friend), professional medical (e.g. oncologist), and professional psychosocial (e.g. social worker) supports. Main themes were identified and described, and relevant scenes were extracted into an educational DVD. Film depicts an unrealistic, bleak picture of childhood cancer, with a 66% mortality rate among the 35 characters evaluated. A range of psychosocial stressors are reflected that are consistent with those experienced in reality. Psychosocial support is limited to resources already available to families prior to the cancer diagnosis: the average support rating across all 29 films is 2.4 for non-professional internal and external supports, 1.6 for professional medical supports, and 0.3 for professional psychosocial supports. Seven themes emerged on the screen: disruption, social impact, psychological impact, physical toll, struggle/war/fight, coping, and barren landscape. Images of an isolated family courageously battling cancer alone with limited support from a treatment team solely dedicated to medical care is emphasized. In conclusion, cinema highlights the struggle between life and death in pediatric cancer, but minimizes the importance of the psychosocial dimension of care, which can perpetuate the stigma that exists around psychosocial interventions. These films, and the included DVD, can be used to encourage discussion among medical providers about how to optimize psychosocial care in pediatric oncology so that such care is not abandoned in actual practice as it is, for entertainment purposes, on the screen.

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Certain things leave you in your life and certain things stay with you. And that's why we're all interested in movies-those ones that make you feel, you still think about. Because it gave you such an emotional response, it's actually part of your emotional make-up, in a way.

- Tim Burton

It's funny how the colors of the real world only seem really real when you watch them on a screen.

- Anthony Burgess

Social reality is so organized that we do not routinely inquire into the meanings of illness any more than we regularly analyze the structure of our social world.[...]The biomedical system replaces [the] allegedly "soft," therefore devalued, psychosocial concern with meanings with the scientifically "hard," therefore overvalued, technical quest for the control of symptoms. This pernicious value transformation is a serious failing of modern medicine: it disables the healer and disempowers the chronically ill.

- Arthur Kleinman in *The Illness Narratives: Suffering, Healing, and the Human Condition*

Tomorrow you'll experience something I've never known. Today you impress me. I feel so tiny before what you'll undergo. It's your life not mine. I respect it more than anything.

- Romeo to his son with cancer in *Declaration of War* (2011)

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I. INTRODUCTION

MEDICAL DISCOURSE AND THE ILLNESS NARRATIVE IN MEDIA: LOOKING IN THE CELLULOID¹ MIRROR

As one of the most potent and substantial forms of mass communication, film creates the “ultimate waking dream experience,” inducing in viewers a dissociative state² in which they become active participants in the narrative, free to play any role they choose in the alternate reality world created within the confines of the movie-house (3, 4). Unlike other forms of media, this unique ability of film to engage viewers in an audiovisual narrative forces viewers to become captive to the film’s visual and aural transmission of cultural beliefs and attitudes (3). Through the dissociative state, viewers enter the screen, and develop strong emotional reactions, opinions, and character identifications within the film reality. In this way, film, as a “mirror” reflecting a distorted, but very real-appearing world, reveals societal norms and values, and, at the same time, exercises a significant influence upon the perceptions of the audience, powerfully affecting human behavior and attitudes. While film audiences are captive to the beliefs and attitudes reflected in the film experience, they are not always passive, gullible recipients of this information. In more contemporary mass communication theories, audiences are thought to be active viewers, rationally and selectively attending to and interpreting the film experience within their own unique framework of knowledge in order to develop a comprehensive world view that is in line with contemporary paradigms (3, 5).

Given this powerful ability of film to portray realistic narratives to a large audience, it has become a popular medium for satisfying the nation’s interest in medical dramas (6, 7). Since as early as the 1920s, medical topics ranging from psychiatric illnesses, infectious diseases, degenerative dementias, and cancers have flooded the screens. These audiovisual images of

¹ Celluloid: the cinema or motion-picture film; of or portrayed on film or in motion pictures (1).

² Dissociative state: a detachment from reality. “The [film] viewer experiences a state in which ordinary existence is temporarily suspended, serving as a ‘psychological clutch’ in which the individual escapes from the stressors, conflicts, and worries of the day (2-4).

medicine generate a public awareness of what it means to be sick and what constitutes the process of healing (7). Such images reflect the personal and social context of illness and medical care, and allow for a holistic view of patient experiences with illness. They create the perfect medium for moving away from the reductionist view of illness founded in the biomedical focus on bodies to a world fascinated with an illness narrative that focuses on the meanings of illness to those who experience it (8-10). Despite this ability for film to reflect a biopsychosocial model of illness, film's primary role as entertainment, not medical education, means that the illness narratives it portrays are both a product of the entertainment demands of the film industry as well as dramatized attempts to create emotional stimulation for a large and diverse audience (9). Nevertheless, the audience utilizes the culturally available illness narratives in film combined with their personal experiences to generate an understanding of "what it is like to be sick, what causes illness, health and cure, how health care providers behave (or ought to) and the nature of health policies and their impact" (9). In this way, a self identity, public perception, and discourse surrounding illness is created, and is brought by patients to the medical scene. Within this scene, it may affect patients' understanding of illness, treatment, outcomes, and health decision-making. Therefore, it is especially important to study the depiction of illness narratives in film so that an understanding can be developed about how these depictions play a role in constructing and influencing patients' illness experiences and expectations of health care (11).

A. Childhood Cancer Now Appropriate for the Screen

Although medical themes have always been popular in the movies, with over 150 such films released between 1930 and 1999, cancer was a topic in only 20 of those films, the majority of which were released after 1970 (12). This historical trend reflects the reluctance of society to invoke the "C-word" in the first half of the twentieth century (13). At that time, cancerphobia³

³ Cancerphobia: Fear of cancer that was especially pervasive in the early twentieth century. This fear stemmed from the belief, by doctors and laymen alike, that cancer was an alien and living invader that assaulted at random and gave little or no warning before "eating" into people (14).

was deeply rooted in American culture (14). Cancer was a dreaded disease, a death sentence that frequently brought with it gruesome and disfiguring changes to the body, all concepts that were not appropriate for the early cinematic experience (13, 14). This began to change by the middle of the twentieth century when “the fairy godmother of medical research”—the professional socialite, philanthropist, and medical activist, Mary Lasker—joined with her husband, Albert Lasker, an intuitive genius in advertising, to “[unleash] the [untapped] power of medical research to combat disease” (15). They transformed the small, self-contained, medically-oriented American Society for the Control of Cancer into a highly organized lobbying group, the American Cancer Society (ACS), which utilized the cancer research establishment, patient advocacy, and support from businessmen, admen, pharmaceutical executives, lawyers, and movie producers to attract attention to and raise funds for cancer research. Such education, lobbying, and media campaigns by organizations like the ACS raised public awareness about cancer care and prevention, and amplified the research community, leading to large improvements in care that made cancer a treatable disease (15). With cancer out of its secretive arena, films with oncology themes began to multiply, particularly in the 1990s. As film narratives often work by creating and exploiting oppositions—heroes and villains, pleasure and pain, beautiful and ugly—cancer turned into a perfect topic for the screen, drawing on the most fundamental opposition to face every human being, that between life and the threat, or actuality, of death (9). In this context, a particularly potent image emerged on the media scene—that of the sick child whose vulnerability and innocent hope for the future are threatened by illness and death (11).

On the screen, one of the earliest images of a childhood cancer patient was that of a 5-year-old girl in the 1952 film *Emergency Call*. She suffers from a “rare blood disease,” leukemia, and has only days to live unless she is able to receive a massive blood transfusion requiring three donors. Unfortunately, she has one of the rarest blood types. A race against time ensues to locate and convince three donors—a white boxer, a black sailor, and a murderer—to save the young, innocent girl’s life. The film centers on the intricacies of good versus evil and interracial blood

donation, with little depth for the complex effects of the diagnosis for the patient and her mother. The complicated and, at times, cruel outside world in this film is in harsh contrast to the hospital world made up of the young, compassionate Dr. Carter, a team of caring nurses, a courageous mother who channels her grief to fight for her daughter's life, and a frail and vulnerable, but always model sick child. Once that cruel world is conquered and the blood donations obtained, she is transfused and cured of the illness that acutely invaded and threatened her life.

This early ideal of miraculous cures and happy endings for young children was not maintained in cinema, as the very few films portraying childhood cancer in the next 40 years, such as *Pete 'n' Tillie* (1972), *The Fourth Wish* (1976), *Forever and Beyond* (1981), and *Six Weeks* (1982), all portrayed young patients doomed to die by this invasive and tragic disease. Such black and white depictions of cancer on the screen—which focused solely on the divide between illness and health and death and cure—faded as public knowledge of cancer and the population of cancer survivors grew, particularly in the 1990s. The growing number of films portraying childhood cancer patients at this time pushed beyond the words cancer and leukemia, and started to show images of children with cancer—how the disease invaded their bodies, its physical and psychological effects, the long treatment course, and the more unclear divide between cure and death. In the last two decades, childhood cancer became a celluloid image readily available to the public, fraught with all of its complexities, ethical dilemmas, psychological stressors, and physical and emotional tolls. Despite the growing presence of childhood cancer on the screen, there has been little analysis of these cinematic images, and thus little understanding of how childhood cancer is portrayed to the general public by film.

B. Shift from the Medical to the Psychosocial

As cinematic depictions of the childhood cancer experience proliferated over the last six decades, so did knowledge of cancer epidemiology, pathophysiology, and treatment. Although a rare disease, the incidence of childhood cancer has continued to slowly increase, with

approximately 12,000 new diagnoses each year in the United States in those less than 19 years of age. Despite the slow rise in incidence, large national and international collaborative research efforts have led to impressive improvements in outcomes. For example, originally a death sentence with 5-year survival rates below 5% in the 1950s, leukemia has become a largely curable disease with the most recent 5-year survival rate of 84% in 2009 for children 0-19 years of age. Overall childhood cancer survival rates have increased from 20% in 1950 to approximately 60% in the 1970s, to 83% in 2009 (16). Despite this success story, cancer continues to be the most common cause of death by disease for children and adolescents in America, accounting for 12% of deaths among children younger than 15 years of age (16). Additionally, while treatments have improved and now include options like chemotherapy, radiation, surgery, stem cell/bone marrow transplant, or a combination of those, completing a treatment course typically requires many years of hospital visits, uncomfortable and long-lasting side effects, frightening procedures, and a severe disruption to the child's life. Therefore, the diagnosis of cancer continues to be a difficult one to bear for children and families as they are confronted both with the possibility of death as well as a long and arduous treatment course that permanently thrusts them into the "culture of childhood cancer" (17).

With improved survival of childhood cancer patients, there arose a need for a better understanding of how children and families adapt to the stressors initiated by a pediatric cancer diagnosis and treatment course (18). The field of psycho-oncology, which concerned itself with these issues, emerged in the mid-1970s, at a time when physicians began to tell adult patients their cancer diagnosis, thus allowing patients' feelings about their illness to be explored for the first time (19). Soon after, this field extended itself to pediatric patients, making large advancements in understanding the psychological assessment of pediatric cancer patients and the psychosocial adaptation of children and families to cancer treatment and survivorship. Research delved into topics of bereavement, distress related to medical procedures, impact of treatment on the entire family—including parents, siblings, and the extended family and social network—the

impact of treatments on neurocognitive functioning, and communication among physicians, parents, and children about their disease and treatment. The limited psychosocial support for children with cancer, provided mostly by nurses and families in the 1950s—reflected in the film, *Emergency Call* (1957)—transformed over the last three decades into a comprehensive model of care founded in a collaboration between medical staff and behavioral teams composed of the disciplines of psychiatry, psychology, child life, education, creative arts, chaplaincy, and social work (20). In 1991, the Working Committee on Psychosocial Issues of the International Society of Pediatric Oncology (SIOP) was established to bring together annually this multidisciplinary group of experts from throughout the world to develop, discuss, and publish guidelines for psychosocial care and intervention. To date, they have set specific guidelines for health-care professionals in areas such as family support, school and education involvement, sibling support, and support at the end-of-life (21). Through such efforts, the field of psycho-oncology gained increasing importance, working to provide appropriate interventions in psychosocial coping and adjustment to improve quality of life throughout treatment and for the growing population of childhood cancer survivors.

Despite these advancements in the field of pediatric psycho-oncology, the availability and acceptance of psychosocial support services continues to vary widely across the United States and internationally. In a study of Children's Oncology Group (COG) institutions, it was found that fewer than 50% of families were offered a meeting with a psychologist and, if offered, the timing of that meeting (at diagnosis or once concern about a psychological problem arose) varied among institutions. Additionally, only 11% of the institutions surveyed implemented evidence-based psychosocial services, and greater than two-thirds of institutions indicated that they had not discussed evidence-based interventions when it came to psychosocial care (22). Another study of 187 COG sites found that psychosocial support teams were available in 80% of the institutions, and included social workers (84%), spiritual care workers (46%), and psychologists (46%), but a palliative care team was available at only 58% of the institutions (23). Findings in countries

outside of the United States generally show lower comfort with the provision of psychosocial services. In a study of physicians and nurses in Ireland, both groups of medical providers appropriately identified the psychosocial care needs of patients and families with physicians seeing themselves as the gatekeepers for the provision of mental health services, but both felt a lack of confidence in their knowledge of the available psychosocial services and had little formal training in relation to psychosocial issues or care. They further identified reluctance on behalf of certain families to take part in psychosocial care due to a stigma attached to psychosocial treatments and misunderstanding regarding the goal or nature of the interventions (24).

Therefore, there is still work to be done to ensure that the scientific progress made in pediatric psycho-oncology is effectively applied clinically across all institutions caring for pediatric patients with cancer. To this end, discussion around, and implementation of evidence-based psychosocial interventions, as well as standardized training of providers in pediatric oncology, will be necessary. As suggested by the Irish study, a large barrier to this comprehensive provision of psychosocial services continues to be the public stigma associated with being labeled as a person who needs psychological help (19, 24). To confront this barrier, providers of psychosocial care must understand and be aware of the origins and culture behind the stigma. Such awareness will allow psychosocial service provision to be seamlessly and fully integrated into oncologic services early in the treatment process so that, regardless of the presence or development of psychopathology at any point throughout treatment, all patients and families will benefit from the provision of psychosocial services, with the “dose” depending on the identified need. This will create an expectation for the practice of psychosocial care within pediatric oncology and minimize the stigma associated with asking for psychological help (19, 22).

To achieve these goals, providers must be aware of the underlying provider, patient, family, and community perceptions toward psychosocial care and the ways in which these perceptions are generated and perpetuated. Personal experiences, scientific training, as well as exposure to media portrayals of psychosocial care—which can be especially unrealistic, outdated,

biased, or lacking in depth—all contribute, as explained previously, to the general public discourse that is brought to the medical arena. The unique features of pediatric cancer versus other chronic illnesses faced by children—the imminent threat of death whose occurrence is difficult to predict, a treatment course that can itself be harmful, a lack of knowledge about the specific cause that creates feelings of helplessness and loss of control, and the significant disruption in daily life routines caused by the treatment process—infuse each childhood cancer experience with an unwelcome ambiguity. This allows for many powerful and unique personal illness narratives to emerge in pediatric cancer. Media, particularly film, thrives on exposing this personal context of the pediatric cancer narrative. Such images perpetuated in the media can be analyzed within a biopsychosocial framework of knowledge to understand how the media approaches the inherent ambiguity in each aspect of pediatric cancer. Such an understanding will allow media to serve as a teaching tool for providers to promote discussions about how to provide the most effective biopsychosocial care.

C. How and why is Health Studied in Film?

Studying health narratives through media, particularly film, as explained previously, is not new (3, 4, 6, 7, 11-13, 25-33). In the majority of studies, a descriptive, thematic approach is undertaken to explain the complex shape that a particular illness or treatment has taken on the screen. Studies explore how an illness or treatment in film has changed over time, how it compares to reality, and what inferences can be drawn about the meaning of these cinematic depictions for general public medical knowledge and for health care administration (3, 12, 13, 25-33). For example, 22 currently available films that directly refer to electroconvulsive therapy (ECT) were analyzed to explore the main themes that appear (29). A cinematic image of ECT emerged highlighting it as an inhumane treatment that represents the futile attempts of society to control and suppress the individual. Not only does such an image have little in common with ECT as currently practiced, but, the authors argue, it propagates a predominantly negative public view

toward ECT treatment. Filmgoers with little personal experience with the treatment cannot distinguish between the demands of the film narrative and clinical reality (29). A similar study of epilepsy portrayal in 23 films identified as showing seizures found that, because of the demands of the film narrative, epilepsy is primarily depicted as “one dimension of unsympathetic, out-of-control, and feared characters,” an image that is outdated and unrelated to current treatment and symptom control. The authors here urge clinical advocacy for more accurate portrayals that will diminish the public fear toward epilepsy patients (32).

Other studies, particularly of medical television dramas, have expanded on this thematic approach with quantitative content analysis of the images of illness, sick bodies, treatments, and outcomes on the screen (34, 35). Such a study of the television programs *ER*, *Chicago Hope*, and *Rescue 911*, which looked at occurrences of cardiopulmonary resuscitation (CPR), found that CPR on such shows was utilized for a much younger, generally healthier population, that long-term survival was significantly higher than in medical literature (67% versus 2-15%, respectively), and that residual effects were minimal, suggesting that CPR is a risk-free treatment. The authors suggest that such portrayals foster a trust in miracles among the public and an expectation from patients and families that CPR be done in all circumstances and be largely successful. Given the physical and psychological harm that this can have on patients, the authors argue that physicians must recognize and acknowledge the images the media presents and address them with their patients (34). A more current study of the television dramas *ER* and *Grey's Anatomy* found that both shows contribute more time to injuries (41%) than to chronic diseases such as cardiovascular disease (11%), cancer (7%), or diabetes, which is practically absent from the screen. The authors argue for media to focus on such chronic illnesses, which account for 70% of deaths in the United States and significantly impact patient's quality of life (35).

Collectively, these studies demonstrate that the entertainment needs of the film or television industry drive and distort the illness narratives that are presented. Film's goal is to satisfy the demands of the plot, time limit, and audience interest and attention-span rather than

medical accuracy. Nevertheless, studies have shown that audiovisual fiction can distort viewers' perceptions of reality⁴ (34, 39-44). Given the root of medicine in the scientific, and therefore, factual realm, audiences may be inclined to take medical information presented in film as fact, and use film, albeit cautiously at times, as a source of medical information. Walter et al. in 2002 surveyed medical students about their views toward ECT prior to and after viewing five movie clips referencing ECT. After viewing the film clips, one third of students decreased their original support for ECT, and the percentage of students who would dissuade a family member or friend from having ECT rose from <10% to 25% (45). If film exerts such a strong influence on medically trained individuals, it undoubtedly serves as a source of medical education for the general public. In a survey of 72 lay viewers who watched 22 key scenes from 17 movies with actors depicting prolonged coma, it was found that viewers missed identifying inaccurate representations of coma in 36% of scenes, and that 39% of viewers could potentially allow these scenes to influence decisions in real life (33). When the popular British soap opera *Coronation Street*, featuring a character with Alzheimer's dementia was broadcast together with the number of the British Alzheimer Society helpline, calls peaked to an absolute record on the evening of the character's diagnosis (31). Similarly, when the movie series *Saw* began a publicity campaign for blood donation ("Give till it hurts!"), 38,000 blood donations were offered by fans of the film (27). Film becomes a particularly important source of information for diseases to which the public has limited exposure outside of the cinematic experience. Like ECT, few individuals have

⁴ There exist multiple theories to explain the relationship between audiovisual fiction and perceptions of reality. One is the extensively studied and critiqued cultivation theory, proposed by Gerbner and Gross, which argues that individuals who spend more time viewing television are more likely to produce judgments which reflect the reality shown on television (36, 37). Another, proposed by Shapiro and Lang, suggests that people remember "event memories" but forget information about context (which should tell them that the memory is based on fiction)—a " sleeper effect" when it comes to addressing the sources that go into forming concepts of social reality (38). A separate perspective is based in the fact that "people tend to form impressions on-line," which refers to a stimulus-based judgment through which people do not respond to the televised situation as they would to a real situation, but they do respond to the concept of the real situation (39). As movies and television dramas suggest in many ways that what they show mimics reality, viewers come to expect and demand a high level of "apparent facticity," and knowingly make inferences about reality while watching movie and television fiction (40).

direct experience with a pediatric patient with cancer, and therefore, the public view of the pediatric cancer experience is largely built on its media depictions.

Given that perceptions of pediatric oncology care can be informed by media portrayals, which can be unrealistic, outdated, or biased by the demands of the entertainment industry, it is important to systematically evaluate the cinematic depictions of childhood cancer, a study that has yet to be done. First, as explained, film offers a unique opportunity among different types of media to truly see the personal experience of a child with cancer, which, when analyzed, can help health care providers understand the systems of knowledge and discourse around pediatric cancer that exist in popular culture. This understanding is invaluable when addressing patients whose own illness experience and decision-making is based on this cultural paradigm established by film. Additionally, images of the pediatric cancer illness narrative presented in film can provide tools for the much-needed teaching of good psychosocial care for pediatric oncology providers. Film offers medical providers an avenue through which to appreciate the “diverse elements that reflect how a person feels when he or she becomes ill and how vital problems are experienced, the influence of spirituality, of surroundings and of the social networks in which the person participates” (46). Because of this, cinemeducation⁵ in medicine has become particularly popular as cinema has been recognized to aptly reflect the materialization, circumstances, and individual and social context in which disease happens, becoming the perfect medium for describing disease as an individual experience and social phenomenon, not just as a biological fact (49). For example, an educational curriculum based on films like *The Doctor* (1991) and *Wit* (2001) is suggested as a means for teaching the complex ethical, emotional, communication, and self-reflection concepts inherent in palliative care medicine (46). Furthermore, film has been shown to be a vehicle for developing empathy and altruism in medical students and residents, giving the learner “the luxury of experiencing emotions for which he or she bears no accountability in the

⁵ Cinemeducation refers to the use of movie clips or whole movies to help educate medical learners about bio-psycho-social-spiritual aspects of health care (47, 48).

real world. Emotions that in clinical settings are perceived as distracting, perhaps dangerous, now become cathartic, and even enjoyable in their full expression” (50). In this context, the concepts of psycho-oncology are perfectly suited for analysis through the cinematic experience. Such an analysis can open avenues for teaching concepts in the psychosocial care of pediatric patients with cancer to medical providers.

D. The Meta-Narrative⁶ of Childhood Cancer

While there have been few analyses of how film portrays the pediatric cancer illness experience, research has addressed the depiction of pediatric cancer in other media, specifically in newspaper accounts and in magazines (52, 53). Such qualitative studies have found that the written pediatric cancer experience is primarily “eulogizing,” emphasizing the heroic character of the child who is presented as “courageous, stoical, and inspirational.” Unlike parental reports, which stress that children can be distressed and difficult to manage, written accounts suggest that they are cheerful, uncomplaining, and brave in their cancer experience. Parents are portrayed as the “confederates in the battle against cancer,” with their self-sacrifice and endless optimism highlighted and limited attention given to their own needs. While newspaper accounts addressed the following five themes—characteristics of a child with cancer, the entitlements of childhood, qualities and resources required in coping with childhood cancer, effects of the childhood cancer on parents and siblings, and struggle—the authors worry that the romanticized and idealized images of the successful family life and coping eventually attained by the families of children with such a serious illness in written accounts can be oppressive to the children and families who find themselves unable to cope in the same way (53, 54).

To gain a comprehensive understanding of the popular culture surrounding pediatric cancer, multiple media sources must be analyzed, and a systematic comparison undertaken between media accounts and the accounts of those directly affected by the childhood cancer

⁶ Meta-narrative: “A global or totalizing cultural narrative schema which orders and explains knowledge and experience”—a narrative about narratives (51).

experience (53). In this way, a meta-narrative of the pediatric cancer experience in media can be developed. Analysis of pediatric cancer in film will expand on the contributions that research of written accounts has added to the development of this meta-narrative. A preliminary study, published only as an abstract, which specifically focused on movie depictions of cancer in children, adolescents, and young adults, found that movies portrayed dismal and unrealistic outcomes, with a 25% overall survival rate, based on 30 evaluable subjects (55). This study, however, provided no information on the images and discourse surrounding pediatric cancer in cinema or on the concept of psycho-oncology on the screen, topics that have yet to be addressed by current research.

In summary, film is a powerful medium for sharing illness narratives, particularly the personal and social context of the illness experience (9, 46, 49). Although modern theory recognizes audiences as active and thoughtful viewers who assimilate information presented through film within their baseline framework of knowledge, the presentation of health content in film, like in television, works to create a social reality of illness and medical care to which viewers are exposed, and medical information, grounded in scientific validity, may be more likely accepted by viewers as fact (36-40, 42, 56). Therefore, movies depicting medical topics can exercise a significant influence on the public's perception and understanding of the illness experience, their expectations for treatment and outcomes, and their health decision-making. An illness narrative that has more recently emerged on the screen is that of the child with cancer. Over the last six decades, this narrative has been infused with the ethical, social, psychological, and physical complexities inherent in the cancer experience. While preliminary research has shown that movies depict unrealistic, dismal outcomes in pediatric cancer with little improvement over time, there has yet to be a systematic evaluation of the holistic cinematic pediatric cancer experience, particularly the role of the growing field of psycho-oncology on the screen. This study will present such an analysis. Both quantitative and qualitative research methods found in

other studies of health in media will be utilized to provide a comprehensive, descriptive review of the pediatric cancer experience portrayed in contemporary, popular film. Analysis will seek to confirm the bleak outcomes portrayed in film, to analyze the psychosocial context of the illness experience, and to address the types of psychosocial support provided to childhood cancer patients and their families emphasized by film. Such an analysis will contribute to the growing meta-narrative about pediatric cancer in media, building an understanding among medical providers of the public perceptions surrounding the pediatric cancer experience and how it reflects current practices and standards. Furthermore, it will provide a framework through which these films can be utilized to teach providers in pediatric oncology about the significant biopsychosocial subtleties and complexities of the pediatric cancer experience.

II. STATEMENT OF PURPOSE / HYPOTHESES / AIMS

A. Purpose

To conduct a systematic quantitative and qualitative analysis of commercially produced and readily available films with at least one character with childhood cancer in order to study the celluloid childhood cancer experience, particularly focusing on psychosocial care. Further, to describe how these cinematic images reflect current standards in pediatric psycho-oncology, what they can teach pediatric oncology providers, and what inferences can be drawn from them about societal perceptions of psychosocial care in pediatric cancer.

B. Hypotheses

1. Cinema paints a bleak picture of childhood cancer with a predominance of untreatable cases with poor outcomes, which is inconsistent with clinical reality.
2. Although film portrays childhood cancer patients and their families as experiencing a wide range of psychosocial stressors, cinematic depiction of psychosocial supports available to them to deal with these stressors largely focuses on resources that are already available to families prior to their diagnosis (close family and friends), rather than professional psychosocial supports (physicians, nurses, psychiatrists, social workers, child life, etc.).
3. Film thus provides an unrealistic view of the use and availability of psychosocial services in pediatric oncology, perpetuating the image of an isolated family courageously battling the stressors associated with caring for a pediatric patient with cancer, and with limited support from a treatment team solely dedicated to medical care.

C. Specific Aims

1. Using quantitative content analysis, systematically evaluate films for: (1) childhood cancer character demographics; (2) medical aspects of the illness and treatment experience; (3) psychosocial stressors experienced by the patients and their families; and (4) psychosocial support characters depicted and their availability and quality.

2. Qualitatively describe common themes in the celluloid childhood cancer experience, with a particular focus on psychosocial stressors encountered, coping mechanisms utilized, and psychosocial support services made available to patients and their families.

3. Compare cinematic depictions of childhood cancer and psychosocial care in childhood cancer to current guidelines and practices, as well as other media analyses to develop the pediatric cancer meta-narrative.

4. Identify and categorize important and relevant scenes from films portraying childhood cancer into an educational DVD that can be used to promote discussion and improve knowledge among medical providers about psychosocial care in pediatric oncology.

III. METHODS

MIXED (QUANTITATIVE AND QUALITATIVE)⁷ MEDIA CONTENT ANALYSIS

This study utilized a combination of quantitative content analysis and qualitative research methodology to analyze media images of the childhood cancer experience propagated through contemporary film.

A. Sample

Commercially and readily available feature-length movies including at least one character with childhood cancer were identified through the advanced title search feature of the IMDB (internet movie database found at www.imdb.com). The following characteristics were used as inclusion criteria for films: (1) feature-length film or documentary; (2) readily available online for purchase through sites like Amazon, iTunes, or Netflix; (3) in English, English-subtitled, or with an English script available; (4) portrays a character under the age of 18 with an explicit or implied cancer diagnosis or involves children with cancer in the plot. The initial film search was conducted by a collaborator, Dr. Nerissa Soh, a research officer at the University of Sydney and Northern Sydney Local Health District, who utilized a variety of search strategies and keyword searches (cancer, child cancer, child with cancer, leukemia, lymphoma, tumor, terminal cancer) to identify a list of potential films, of which 22 fit the above criteria and were initially viewed by the study group. This investigator reviewed Dr. Soh's methods to identify the strategies and keyword combinations that successfully identified relevant films, and used these combinations to run a new search which identified each of the 22 original films as well as seven additional films that fit the above criteria.

⁷ Mixed-methods studies are ones in which qualitative and quantitative methods are combined in a single research design. The complementary strengths of each approach allow the researcher to characterize complex phenomena more fully than either approach alone (57, 58).

The final film selection process is outlined in detail in **Figure 1**. Feature films, documentaries, and videos were believed to have the potential to reach and leave an impression on a large audience. An international rather than national perspective was chosen to allow for an understanding of the cultural influences on the cinematic pediatric cancer experience beyond that of the culture of film itself. All genres were included to provide a comprehensive analysis of the pediatric cancer experience, which plays different roles in

the film narrative in different genres. The three keywords shown in **Figure 1** generated an exhaustive list of films that was not expanded when using other keywords such as “child with cancer,” “cancer patient,” “lymphoma,” “tumor,” “brain tumor,” “blood cancer,” “death from cancer,” or “loss of child”. Films were included only if the plot summary or trailer clearly indicated the presence of a character under the age of 18 who had cancer. The inclusion criteria were then applied to these movies. Six films were excluded because they could not be obtained with English subtitles or scripts, one film was excluded because it was not easily available to the public, and all but one of the documentaries found were excluded because they were not feature-length (greater than 40 minutes). For the final analysis, only movies released after 1990 were included for the following reasons: there were only five feature-length films including a character with childhood cancer released prior to 1990 identified on the IMDB website, these films were not easily available for public purchase and viewing, and the majority of the storyline in each film

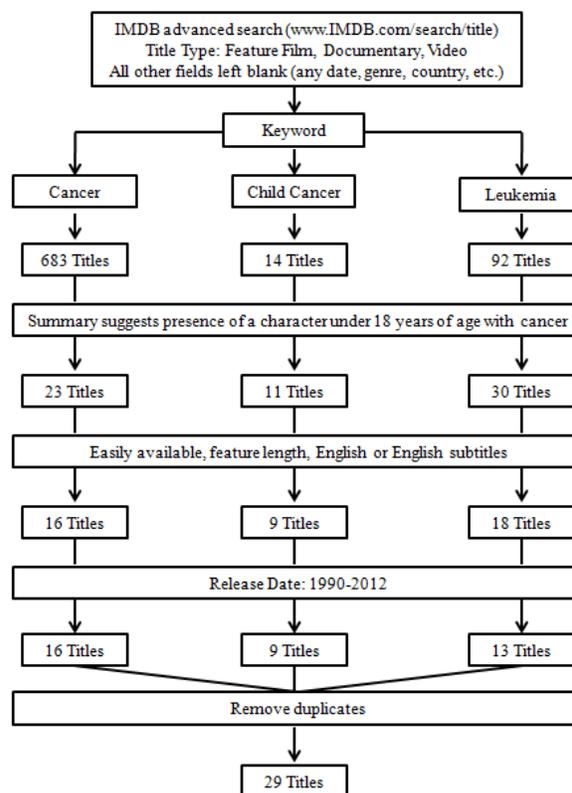


Figure 1. Film Selection

Outlines the method used for identifying the films that were included in the final analysis.

did not directly involve the child with cancer or the cancer experience itself and thus would add little to this analysis. Therefore, this study focused on a contemporary cinematic view of pediatric cancer in film over the past two decades. Of note, four of the five films identified that were released prior to 1990 were obtained and viewed to provide some historical perspective of pediatric cancer in the movies over the past 60 years. This film selection process produced a list of 29 films, all of which were obtained on DVD for viewing. Based on box office data on the IMDB movie database, which was available for 17 of the films, 15 had generated gross revenue greater than one million dollars, suggesting the potential for these films to reach broad and large audiences. While the IMDB is a fairly comprehensive film search engine, some films may have been missed that were either not included on the IMDB website or were not categorized under the keywords searched. Nevertheless, this is still a comprehensive list of films that include a child with cancer released in the last 20 years that are easily available to the public, and it is the most exhaustive one found in the current literature.

B. Film Analysis Instrument

The initial 22 films were first viewed by Dr. Julie Chilton, Assistant Clinical Professor at the Yale Child Study Center, and general notes regarding interesting scenes, specific psychosocial stressors, psychosocial support providers, and themes depicted were taken. Several films were additionally viewed by the principal investigator, Dr. Andrés Martin, a child psychiatrist with a special interest in the psychosocial care of pediatric cancer patients. These investigators developed a preliminary schema for evaluating psychosocial support in the films, and identified potentially relevant themes, results which were presented via a poster (59). Their experiences and data collection were discussed among the study group and utilized to plan a more standardized schema for a second evaluation of all 29 films by this investigator, a fourth-year Yale medical student who has an interest in pediatric oncology and long-term experiences with two patients undergoing cancer treatment.

This investigator used the prior work, team discussions, relevant literature about medical and psychosocial care in pediatric oncology, and a focus on the general hypotheses and study purpose to create a film analysis instrument that would be comprehensive, detailed, flexible, and convenient. The instrument should be comprehensive enough to gather all relevant information about the medical aspects, psychosocial stress, psychosocial support providers, interactions between the providers and the patient, and themes depicted in a film in one document that is easy to fill out. Headings, subheadings, and checkboxes should be created for each major category of information to ensure that specific data are recorded about each film and that the same level of detail is recorded about each film regardless of the state of the viewer watching the film and his/her subjective viewing experience. The film analysis instrument should have enough flexibility through free text space to allow specific details about the image of pediatric cancer patients, the stresses they experience, and their interactions with the medical team to be captured without any restrictions from pre-conceived notions of what will be depicted or will be important. It need also be applicable to a variety of film types and childhood cancer roles so that it can be used for each of the 29 films. Finally, the film analysis instrument should be created in such a way that one can conveniently extract information needed to answer the research questions, to group information together, to code information, and to analyze the information statistically.

With these goals in mind and the experience of viewing five of the films, a Microsoft Access database was created. For each movie, information about multiple characters could be added if there was more than one child with cancer depicted. For each character, one domain of the film analysis instrument covered demographic and medical information, including age, gender, diagnosis, symptoms, treatment, treatment side-effects, complications, discussions of diagnosis, prognosis, and treatment, and overall outcome. A second domain was concerned with psychosocial stressors, including any psychopathology depicted in the film as well as a listing of stressors for each character type (patient, parent, sibling). Additional information about general categories of stress like social, religious, financial, and school were also included. A third domain

was dedicated to listing the psychosocial supporters depicted in the film, the type of role they played, and their rating in terms of presence, involvement, and efficacy. Finally, a fourth domain included a text box for listing general themes that were relevant to the particular film. Except for this final theme section, the remainder of the data sheet was patient-specific rather than movie-specific. A detailed example of the film analysis instrument can be found in **Appendix A**, and specific information about each variable in the instrument will be provided in section D.

C. Procedure

Each of the 29 films was viewed by this investigator over a one month period of time, with a maximum of two films per day.

Detailed Chronological Picture

During the initial viewing, detailed chronological notes were taken of the whole movie, with a particular focus on the depiction of the child with cancer and aspects of the story relevant to the child, his family, and the cancer experience (what was said, what the environment looked like, who was involved, what were the interactions like, what were the emotions elicited, etc.). Specific times of important scenes were recorded, relevant dialogue was transcribed, and general thoughts about the film were noted. This initial viewing stage focused on transcribing the events, dialogue, images, and emotions depicted by the film with an attempt to limit, as much as possible, any subjective interpretation of the information.

Detailed Organized Picture

Subsequently, the information from the detailed chronological picture was organized in a film analysis document, a word document in which information was grouped into general sections related to the sections of the film analysis instrument. At this stage, the meaning of the information initially transcribed was interpreted, and this viewer's analysis of the characters, scenes, and dialogue recorded. This generated, for each film, detailed, organized, and comprehensive information about the medical aspects, psychosocial stressors, psychosocial

support characters, and themes depicted in each film. If the other investigators had viewed a film and taken notes, their notes were incorporated at this stage of analysis. **Appendix A** shows an example of a blank film analysis document as well as an example of a completed form for the film *My Sister's Keeper* (2009).

Summarized Organized Picture

The second, organized review of the initial film notes was utilized to fill out the film analysis instrument in the Microsoft Access database. As both the initial view chronological notes and the film analysis document were written with the instrument variables in mind, in most cases, they provided sufficient information to complete the film analysis instrument. In any instances in which this investigator was unsure of a detail, the pertinent scenes from the film were re-watched to confirm that the information entered in the film analysis instrument was accurate. At this stage, all of the data in the film analysis document were further interpreted and condensed, either through checklists or summary phrases which were developed and modified as all of the films were watched. **Appendix A** also provides an example of the completed film analysis instrument for the film *My Sister's Keeper* (2009) so one can see the progression from the initial view notes to the film analysis document notes to the final film analysis instrument.

As described, the detailed chronological picture was taken by this viewer at the time of film viewing and was as comprehensive and detailed as possible. For the majority of films, the detailed organized picture and the summarized organized picture were completed within at most one week (typically two days) of film viewing so that the information was fresh in this viewer's mind, with limited opportunity for confusion caused by viewing of additional similar films. However, the first five films were viewed two weeks prior to the creation of the film analysis instrument and thus may not have had as relevant or structured initial view and film analysis document notes. These were re-watched to confirm consistent analysis among the older and more recently viewed films when it came to the film analysis instrument.

Generally, an iterative process of simultaneous data collection and analysis occurred so that prior films informed and refined future data collection. The instrument variables generally remained the same, but the specific information recorded and the structure in which it was recorded were modified to allow for different film types to be analyzed with sufficient detail. As new films were watched and generated new ideas for important points of discussion or analysis, earlier films were re-visited to include this new information. This inductive approach, through which the structure in which analysis occurs is iteratively refined by review of data, ensured that all films were equally analyzed and interpreted and that the structure for analysis was grounded in the films themselves rather than on the viewer's preconceived concepts about the data⁸.

D. Instrument Variables: Data Collection and Analysis

Film Information

For each film, information about year of release, genre, running time, country of production, language, release and sales information, and awards were solely obtained from the IMDB movie database. The role that the child with cancer played in the film was categorized as:

- Leading: Major character in the film / film narrative is principally about this character
- Supportive: Major character in the film but not the focus of the film narrative
- Minor: Not a main character in the film

The role that the cancer storyline played in the film narrative was categorized as:

- Main: Plays a significant role in the film narrative and is required by the film narrative
- Secondary: Plays a significant role in the film narrative, but is not required
- Minor: Does not play a significant role in the film narrative

Childhood Cancer Characters' Demographic and Medical Information

⁸ The general research approach was based on the Grounded Theory developed by Barney G. Glaser and Anselm L. Strauss. Grounded Theory serves as a general methodology for conducting rigorous qualitative research. Through the continuous interplay between analysis and data collection, theory evolves during actual research and is grounded in data systematically gathered and analyzed (60). The inductive approach to structuring data is fundamental to this process. The coding structure for each variable emerges through scene by scene review of each film, and this prevents researchers from forcing preconceived results on to the data. This is in contrast to a deductive approach, which starts with an organizing framework for the codes prior to data review, and is more useful for integrating concepts already well known in the extant literature (61).

For each childhood character with cancer, their name, sex (male/female), and age was recorded. The exact age was recorded when stated in the film. In the rare instances in which it was not clearly stated, this viewer subjectively placed the character in one of the following age categories: young child (1-6 years of age), pre-teenager (7-12 years of age), teenager (13-18 years of age). The cancer diagnosis was recorded exactly as specified in the film. After review of all diagnoses, they were grouped into four mutually exclusive categories: leukemia, lymphoma, CNS/brain tumor, and cancer unspecified. The last category included films in which the general term “cancer” was used as well as one film in which the diagnosis was never clearly stated, but was believed to be obviously cancer based on the narrative. Cancer symptoms included any medical symptoms observed by the viewer either prior to diagnosis or after diagnosis but not related chronologically, verbally, or clinically to the administration of any treatment. Symptoms could not be secondary to any other obvious cause such as acute trauma. The symptoms were later grouped into six categories that were exhaustive for all of the types of symptoms depicted in film. Treatment modalities were checked off if the childhood cancer character was observed receiving the treatment or if the film mentioned that the patient had received the treatment. Treatment side effects included any medical symptoms observed by the viewer directly known to be related to the treatments received by the time course, movie dialogue, or general medical knowledge. Similar to cancer symptoms, these were later grouped into nine categories that were exhaustive for all types of treatment side effects observed in all of the films. Complications were categorized as relapse, metastasis, bone marrow transplant failure, severe infection, or organ failure. Finally, outcomes were categorized as death, living with the disease, or cure/remission. Each of these variables was quantitatively analyzed using descriptive statistics, such as frequencies and proportions.

Psychosocial Stress

For each film, psychosocial stressors were initially written in free-text based on the viewer’s subjective determination with regard to stress experienced by the character with cancer,

the parent, the siblings, as well as general stressors with regard to issues such as school, social life, living situation, finances, and religion that are typically cited as areas of stress for cancer patients and their families. Detailed information with examples was written in the initial view notes, organized and further described in the film analysis document, and summarized into short phrases that were written in the film analysis instrument database. The absence of a pre-defined set of stressors to look for in the films allowed for a more comprehensive evaluation of psychosocial stress in the celluloid childhood cancer experience that was not limited by researchers' expectations for what might be found. The short phrases written in the film analysis instrument were constantly reviewed as new films were added, and codes were assigned to sets of psychosocial stressors that represented the same concept. New codes were assigned as necessary to account for new information until the final film was viewed or the point of theoretical saturation⁹ was reached. Through this inductive and iterative process, a structure for organizing psychosocial stressors for children with cancer, the parents, and the siblings was created that was grounded in the film viewing experience and was exhaustive for the types of stressors presented in all of the films. After the completion of this structure, films were re-evaluated and the presence or absence of a particular stressor category was confirmed for each character. For each film, it was also specified and confirmed through the film reviews whether the character with cancer or family experienced stress in the areas of school, social life, living situation, religion, or finances. Through the re-evaluation process, it was determined that no major concepts had been left out by the structure created. This qualitative approach to identifying psychosocial stressor categories depicted across the films was augmented with a quantitative approach to describing the data based on frequencies and proportions of films that highlighted each of the identified stressors.

⁹ Theoretical saturation: refers to a point in data collection and analysis at which no new concepts emerge from reviewing the data. It means that the data analysis has fully captured the diverse characteristics of the chosen data, and is exhaustive, including all of the pertinent elements found in the data (61).

Psychosocial Supports

For each film, characters were included as providers of psychosocial support to the child with cancer and his/her family if: the character interacted directly with the child or family in a way that produced an effect on their cancer experience or on their ability to cope with other aspects of their lives that had been affected by the cancer experience; the character was mentioned as a source of support for the childhood cancer character or family; a character was mentioned in the film whose role is generally known to be a potential source of support for patients with cancer even if not explicitly stated in the film. The character was subsequently classified into one of four categories of supporter types based on their relationship to the professional cancer treatment team and the patient (**Table 1**). This was the schema originally designed by Dr. Martin and Dr. Chilton during initial film viewing (59).

Table 1. Sources of Psychosocial Support

Non-Professional		Professional	
Internal	External	Medical	Psychosocial
Parent	Extended family	Oncologist	Psychiatrist, Psychologist
Sibling	Friend	Primary care physician	Mental health nurse
Close family	Significant other	Nurse	Hospice/palliative care specialist
	Teacher, Coach	Specialist	Social work, Child life
	Clergy, Community		Hospital chaplain

The psychosocial support provided by each character identified was then rated using a standardized system of dimensional ordering¹⁰ and spatial models¹¹ so that each character was equally evaluated on a three-point scale for their presence, involvement, and efficacy (**Table 2**). These three dimensions were identified as appropriate measures for evaluating an individual

¹⁰ Dimensional Ordering: Content classified on the basis of a numerical scale, such as intensity (5).

¹¹ Spatial Models: Content described along, for example, a 7-point scale as good-bad, effective-ineffective, and so on. This allows content analysts to explore complex meanings attached to symbols (5).

providing psychosocial support based on a proposed definition of social support as a metaconstruct encompassing the following dimensions: (a) support network resources or the net of relationships through which an individual receives help in dealing with the demands and achieving goals (number of different roles represented, the number of different people in each role, frequency and degree of contact individuals have with network numbers), (b) supportive behaviors or the specific acts intending to help someone, and (c) subjective appraisal of these network resources and behaviors (62).

Table 2. Psychosocial Support Character Rating

	Presence	Involvement	Efficacy
0	Only mentioned; Shown briefly ≤ 2 times	No direct involvement	Does not follow general guidelines ^B Is of limited value; Is detrimental
1	Shown briefly > 2 times; Minor role in patient's illness narrative	Involved in one specific domain of the cancer experience ^A	Follows some general guidelines ^B Somewhat improves the well-being of the patient/family
2	Shown at-length > 2 times; Major role in patient's illness narrative	Involved in several domains of the cancer experience ^A	Follows most general guidelines ^B Greatly improves the well-being of the patient/family

^A Domains of the cancer experience: home life (medical care at home, relationship with family), social life (relationship with friends, maintaining normal childhood activities), school (re-integration, keeping up throughout treatment), hospital life (comfort in the new environment), illness experience (knowledge, coping), treatment experience (distress from procedures, management of treatment side effects)

^B Annual guidelines set forth by the SIOP Working Committee on Psychosocial Issues in Pediatric Cancer (63-73).

With this definition in mind, an algorithm was developed by this investigator through which each film was evaluated on a five-point scale for the quality of psychosocial support depicted in each of the four supporter categories. The standardized algorithm took into account the number of support characters in each category and the collective rating of those characters in the areas of presence, involvement, and efficacy, simulating the meta-construct view of

psychosocial support that forms the basis for the algorithm's validity (**Table 3**). Although the definitions outlined in **Table 2**, particularly that of efficacy, are potentially subjective and based on the viewer's interpretation of whether the supporter, for example, improved the well-being of the patient/family, the categories are broad enough so that a specific supporter typically clearly fell into one of the ratings. Particularly important is that this classification scheme provides a multi-dimensional evaluation of each character providing psychosocial support and of psychosocial support as a whole in each film, thus capturing the complexity inherent in the concept of psychosocial support in a quantitative fashion. Furthermore, the individual character ratings as well as the overall rating of each film in each of the four categories of supporter types remained consistent for this viewer over two separate time points, supporting the reliability of the algorithm.

Themes

For each film, themes were initially written in free-text based on the viewer's subjective determination of the key concepts presented by the film, keeping the general research focus of psychosocial issues and care in mind. For the films that were watched by more than one viewer, all unique themes written by each viewer were combined in the film analysis instrument. Again,

Table 3. Psychosocial Support Film Rating

Algorithm utilized for each film for each of the four categories of sources of psychosocial support

Number	Percent 2s	Percent 0s	Rating
≥ 3	>75%		4
(if more	50-75%		3
than 3,		≤50% ^A	3
take	<50%		
best 3)		>50%	2
	>75%		3
	50-75%		2
2		≤50% ^A	2
	<50%		
		>50%	1
	100%		2
	50-99%		1
1		≤50% ^A	1
	<50%		
		>50%	0

^A As more value was given to involvement and efficacy versus presence, if there was a 50% distribution of 0s and 1s, the higher rating would be given only if the 0s were in the category of presence, otherwise the lower rating would be given because of poor involvement or efficacy.

the absence of a pre-defined set of themes to look for in the films allowed viewers to keep an open mind and ensured that the final thematic structure was grounded on film content rather than viewer's pre-conceived beliefs. The original themes were subsequently reviewed and codes were assigned to groups of themes that represented the same concept in order to standardize the description of the same themes across all of the movies and viewers. These codes were reviewed and discussed among the three investigators to determine the most appropriate structure of themes and subthemes that captured all major concepts in the cinematic pediatric cancer experience. With this structure, films were re-evaluated to confirm the presence or absence of each theme and subtheme, which resulted in a quantitative analysis of the frequency of each concept, and confirmed that no major concepts had been left out by the thematic structure generated. Additionally, the film analysis documents were reviewed for each film, and scenes/dialogue/images that were thought to illustrate a particular theme or subtheme were noted by this viewer. This formed the basis for the qualitative analysis of each theme and subtheme.

E. Development of an Educational DVD

Utilizing a DVD recorder device (Avid Technology Dazzle DVD Recorder HD V14.0), relevant segments from each film that were identified during the initial view were recorded. This served as yet another view of each film with a particular focus on scenes depicting communication between the treatment team and patients and families, images of psychosocial stress, and images of the provision of psychosocial support and care. These scenes were reviewed and discussed among the members of the research team to identify clips that generated meaningful discussion regarding concepts of psychosocial stress, support, and general care in pediatric cancer. Those clips identified as having educational value in discussing psychosocial care in pediatric cancer were organized based on the themes and burned onto a DVD found at the front of this book. In the generation of this material, a subset of movies were overrepresented and were identified as useful films in the teaching of psychosocial care in pediatric cancer.

IV. RESULTS

A. Film Characteristics

Twenty-nine feature-length, commercially available, English or English-subtitled films released after 1990 containing at least one character under the age of 19 with cancer were identified through the IMDB search process. The films represent a wide range of countries, with 22 films produced in the United States, three each in the United Kingdom, France, and Canada, two in Spain, and one each in Germany, Poland, Greece, Mexico, South Korea, and Belgium. Seven of the films involve collaborations between two or more countries. As expected, the majority of films (27/29) are classified by the IMDB as dramas. Of the other two, one film is a feature-length documentary and one is classified as a family film. Four of the 27 drama films are also classified as family, four as thriller/horror/action/crime, four as romance, and two as comedy. While the films selected did not have to have childhood cancer as the main theme of the storyline, in 55% of the films, the character with cancer plays the leading role and, in 65% of the films, childhood cancer plays a main role in the film narrative. In 28% of films, the childhood character with cancer plays a secondary role, and in 17% of films, he/she plays a minor role. Similarly, in 28% of films, cancer plays a secondary role in the film narrative, and in only 7% of films, cancer plays a minor role. **Table 4** lists information about each of the 29 films identified, and the classification of the role played by the childhood cancer character in the film as well as the role played by cancer in the film narrative.

Table 4. Film Characteristics

Title of Movie	Year	Genre	Country	Role of Character with Cancer	Role of Cancer in Film Narrative
The Basketball Diaries	1995	Biography	USA	Minor	Minor
		Crime			
		Drama			

Table 4. Film Characteristics

Title of Movie	Year	Genre	Country	Role of Character with Cancer	Role of Cancer in Film Narrative
The Ride	1997	Drama Family Sport	USA	Leading	Secondary
A Civil Action	1998	Drama Thriller	USA	Minor	Main
Desperate Measures	1998	Action Drama Thriller	USA	Supportive	Main
The Darkest Light	1999	Drama	UK France	Supportive	Secondary
Looking for an Echo	2000	Drama	USA	Supportive	Secondary
Erin Brokovich	2000	Biography Drama Romance	USA	Minor	Main
Stolen Summer	2002	Drama	USA	Supportive	Secondary
A Walk to Remember	2002	Drama Romance	USA	Leading	Secondary
Julie Walking Home / The Healer	2002	Drama Romance	Germany Canada Poland USA	Supportive	Main
Swimming Upstream	2002	Drama	USA	Leading	Main
Birdie and Bogie	2004	Drama Sport	USA	Leading	Secondary

Table 4. Film Characteristics

Title of Movie	Year	Genre	Country	Role of Character with Cancer	Role of Cancer in Film Narrative
The Sisterhood of the Traveling Pants	2005	Comedy Drama	USA Greece Mexico	Minor	Minor
One Last Thing	2005	Comedy Drama	USA	Leading	Main
Hello Brother	2005	Drama	South Korea	Leading	Main
A Lion in the House	2006	Documentary	USA	Leading	Main
The Ultimate Gift	2006	Drama	USA	Supportive	Secondary
Katie's Wish	2007	Drama	USA	Supportive	Main
Camino	2008	Drama	Spain	Leading	Main
Oscar and the Lady in Pink	2009	Drama	France Canada Belgium	Leading	Main
The Haunting in Connecticut	2009	Drama Horror Thriller	USA Canada	Leading	Main
My Sister's Keeper	2009	Drama	USA	Supportive	Main
C Me Dance	2009	Drama Thriller	USA	Leading	Main
Ways to Live Forever	2010	Drama Family	Spain UK	Leading	Main
Letters to God	2010	Drama Family Christian	USA	Leading	Main

Table 4. Film Characteristics

Title of Movie	Year	Genre	Country	Role of Character with Cancer	Role of Cancer in Film Narrative
Johnny	2010	Drama Family	USA	Leading	Main
Snowmen	2010	Family	USA	Leading	Secondary
Declaration of War	2011	Drama	France	Minor	Main
Restless	2011	Drama Romance	USA UK	Leading	Main

B. Childhood Cancer Characters' Characteristics

Table 5. Demographics

(35 child cancer characters in 28 films)

Gender	
Male	22 (63%)
Female	13 (37%)
Age	
1-6	2 (6%)
7-12	18 (51%)
13-18	15 (43%)
Race	
White	31 (88%)
Black	2 (6%)
Asian	2 (6%)

Demographics

Thirty-five distinct characters under the age of 19 with cancer were identified in 28 films. One film, *A Civil Action* (1998), was excluded in the individual analysis of the characters with cancer as it refers to eight children who had passed away from leukemia prior to the start of the film so that there are no direct images of children with cancer. **Table 5** provides demographic information for these 35 childhood cancer characters. The typical image of a patient with childhood cancer, seen in over one-half of the films, is that of a white, pre-adolescent to adolescent boy.

Medical Information

Reflecting current childhood cancer epidemiology, the most common types of cancer presented in film are leukemia and CNS/brain tumor. The character is most commonly diagnosed

after developing weakness and lethargy leading to a syncopal episode, although both bleeding, particularly epistaxis, and focal neurologic changes are a common depiction. For the majority of characters, chemotherapy is presented as a treatment, although the extent and detail to which the chemotherapy is explained and depicted throughout the film is highly variable. Approximately one-third of the characters with childhood cancer receive radiation, one-third undergo stem cell/bone marrow transplant, and one-fourth receive a surgical intervention.

In depicting the side effects of cancer treatments, the most common image is that of hair loss, and for many of the characters, the viewers' only sign of an underlying illness is the character's bald head. Signs of immunosuppression, such as fever or infectious symptoms, and general fatigue and weakness are each shown in one-fourth of characters. Complications commonly occur on the screen, seen for 18/35 characters (51%). One-half of these instances portrayed relapse of the primary tumor and one-fourth revolved around bone marrow transplant failure. Among the 11 characters who were shown or mentioned as receiving a bone marrow transplant, four (36%) had either a poor outcome during the transplant or were said to have rejected the transplant. Mortality secondary to all types of childhood cancers on the screen based on these 35 characters was 66%. There was no change in outcomes depicted on the screen over time. Despite these generally poor outcomes, end-of-life suffering and physical symptoms are infrequently shown, and the majority of films avoid direct images of death or portray death as a peaceful event that occurs in the patient's sleep. In stark contrast to the images of real cancer patients seen in the one documentary, most of the characters in the fictional films maintain good functional capacity up to their death. **Table 6** summarizes the general medical characteristics of the 35 characters studied with regard to diagnosis, cancer symptoms, treatments, treatment side effects, complications, and outcome, and is the source for the above presented information.

Table 6. Medical Information (35 child cancer characters in 28 films)

Diagnosis		Treatment Side Effects	
Leukemia	19 (54%)	Hair Loss	25 (71%)
CNS/ Brain Tumor	8 (23%)	Fatigue / Weakness	10 (29%)
Lymphoma	3 (9%)	Immunosuppression	10 (29%)
Cancer - Unspecified	5 (14%)	Nausea / Vomiting	8 (23%)
Cancer Symptoms		GI / Cutaneous Ulcers	6 (17%)
Fatigue / Paleness / Syncope	15 (43%)	Pain	3 (9%)
Focal Neurologic Findings	8 (23%)	Other ^B	8 (23%)
Bruising / Bleeding	7 (20%)	Complications	
Pain / Headache	6 (17%)	Relapse	9 (26%)
Recurrent / Persistent Fevers	4 (11%)	BMT Failure	4 (11%)
Loss of Appetite / Weight Loss	4 (11%)	Severe Infection	3 (9%)
Treatment		Metastasis	2 (6%)
Chemotherapy	29 (83%)	Organ Failure	2 (6%)
Radiation	12 (34%)	Outcome	
Bone Marrow Transplant	11 (31%)	Death	23 (66%)
Surgery	9 (26%)	Cure / Remission	9 (26%)
Experimental Protocol	6 (17%)	Living with Disease	3 (9%)
Palliative / Comfort Care	4 (11%)		
Other ^A	9 (26%)		

^A Symptom management (Zofran, pain medications, transfusions, dialysis, Amicar); alternative therapies (Reiki, faith healer); and cancer treatments (cord blood transplant, white blood cell infusion).

^B Side effects depicted in 2 or fewer films (diarrhea, blindness, visual hallucinations, erectile dysfunction, graft-versus-host disease, edema, loss of taste, cognitive/neurologic impairment, stroke).

C. Psychosocial Stress

The analysis of psychosocial stress for children, parents, and siblings across the films generated the coding structure seen in **Table 7**. Certain concepts of psychosocial stress were

common to all three populations, while others were unique to each population.

Concepts either represented causes of psychosocial stress or served as a general reflection of the images of daily stress that the character faced on the screen secondary to the illness.

Table 7 additionally shows the number of films that addressed stress in some of the more common areas such as school, social life, finances, living environment, and religion. Overall, cinema portrays childhood cancer patients and their families as experiencing a wide range of psychosocial stressors and the majority of films illustrate multiple stressors.

The concepts identified in this analysis are closely linked with the major thematic categories that emerged in the evaluation of the film themes, and thus

these concepts will be clarified and illustrated in section E. **Appendix B** provides detailed information on which stressors were present in each film and can serve as a guide for identifying films that are particularly strong at depicting each of these concepts of psychosocial stress.

Table 7. Concepts of Psychosocial Stress in Pediatric Cancer Manifested in Film

	Psychosocial Stress Concept	# of Films
Children	Lifestyle Disruption	23 (79.3%)
	Emotional Distress	26 (89.7%)
	Procedures	8 (27.6%)
	Physical Symptoms (pain, hair loss)	18 (62.1%)
	Fear/Anxiety about Outcomes	8 (27.6%)
	Social Isolation (loss of friends, bullying)	24 (92.3%)
	I'm Different (self-esteem challenged)	14 (48.3%)
Parents	Worry about Parents/Family	8 (27.6%)
	Lifestyle Disruption	19 (65.5%)
	Emotional Distress	25 (86.2%)
	Loss of Control	6 (20.7%)
	Maintaining Image of Strength	6 (20.7%)
	Decision-Making (protecting child, guilt)	15 (51.7%)
Siblings (12 films)	Discord with Partner	8 (27.6%)
	Lifestyle Disruption	10 (83.3%)
	Emotional Distress	12 (100%)
	Meeting Parents' Expectations	4 (33.3%)
	Increased Responsibility / Parentification	3 (25.0%)
	Feeling Left Out (medical experience)	6 (50.0%)
General	Neglect (emotional, physical)	7 (58.3%)
	Discord with Parents	7 (58.3%)
	Social	21 (72.4%)
	School	15 (51.7%)
	Financial	11 (41.4%)
	Living Environment	10 (34.5%)
	Religion	6 (20.7%)

D. Psychosocial Support

Psychosocial support was evaluated on a 0 to 4 scale as described in the methods for each of the four supporter categories for each film, and the results are displayed in **Table 8**. Films in general do not show strong psychosocial support for pediatric cancer patients across all categories, with few people involved in providing support and those involved frequently not meeting guidelines, as determined by the SIOP Working Committee (63-73). When films do show strong psychosocial support, it is typically provided by non-professional support characters, either an important individual internal to the patient's support network like a parent, or by a strong external support network of friends, extended family, or a significant other. Of note, the average rating for films in the categories of internal non-professional and external non-professional supporters are both 2.4. For professional medical supporters, the average rating falls to 1.6, and for professional psychosocial supporters, the average rating significantly falls to 0.3. **Figure 2** further summarizes the data, showing the high frequency of low ratings in the professional support categories as compared to the non-professional support categories. Therefore, cinema inadequately addresses psychosocial care for pediatric patients with cancer, and perpetuates a focus on resources that are already available to the family prior to the diagnosis rather than professional psychosocial support providers.

TABLE 8. Psychosocial Support Ratings by Supporter Category

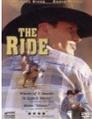
Title/Year/Country	Non-Professional		Professional	
	Internal	External	Medical	Psychosocial
 The Basketball Diaries 1995, USA	0	2	0	0
 The Ride 1997, USA	0	4	0	0

TABLE 8. Psychosocial Support Ratings by Supporter Category

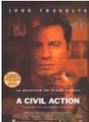
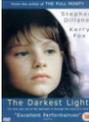
Title/Year/Country	Non-Professional		Professional	
	Internal	External	Medical	Psychosocial
 A Civil Action 1998, USA	0	2	0	0
 Desperate Measures 1998, USA	2	2	3	0
 The Darkest Light 1999, UK/France	3	2	0	0
 Looking for an Echo 2000, USA	3	1	3	0
 Erin Brokovich 2000, USA	3	1	0	0
 Stolen Summer 2002, USA	3	3	1	0
 A Walk to Remember 2002, USA	2	2	0	0
 The Healer / Julie Walking Home 2002, Germany/Canada/Poland/US	4	3	1	0
 Swimming Upstream 2002, USA	2	3	2	0
 Birdie and Bogie 2004, USA	3	2	2	0
 The Sisterhood of Traveling Pants 2005, USA/Greece/Mexico	0	2	0	0

TABLE 8. Psychosocial Support Ratings by Supporter Category

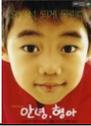
Title/Year/Country	Non-Professional		Professional	
	Internal	External	Medical	Psychosocial
 One Last Thing 2005, USA	2	3	1	1
 Hello Brother 2005, South Korea	4	4	2	0
 A Lion in the House 2006, USA	4	3	4	3
 The Ultimate Gift 2006, USA	2	2	2	0
 Katie's Wish 2007, USA	4	2	1	0
 Camino 2008, Spain	3	3	3	2
 Oscar and the Lady in Pink 2009, France/Canada/Belgium	2	3	3	0
 The Haunting in Connecticut 2009, USA/Canada	3	1	1	0
 My Sister's Keeper 2009, USA	4	2	3	1
 C Me Dance 2009, USA	2	3	1	0
 Ways to Live Forever 2010, Spain/UK	3	4	2	0

TABLE 8. Psychosocial Support Ratings by Supporter Category

Title/Year/Country	Non-Professional		Professional	
	Internal	External	Medical	Psychosocial
 Letters to God 2010, USA	4	3	2	0
 Johnny 2010, USA	0	3	3	3
 Snowmen 2010, USA	2	3	0	0
 Declaration of War 2011, France	4	1	3	0
 Restless 2011, USA/UK	2	2	2	0
Mean Rating Across All 29 Films	2.4	2.4	1.6	0.3
25th Percentile	2	2	0	0
Median	3	2	2	0
75th Percentile	3.5	3	3	0

Non-Professional Support Characters

With regard to internal non-professional supports, 0 to 11 support characters were shown per film (82 total identified in all 29 films) with an average of 2.83 characters per film. The majority of characters in this category were parents (57%), followed by close family (23%), and siblings (18%). Consistent with US statistics from the 2009 census, 27.7% of the parents in film were single parents (74). Films ranged from

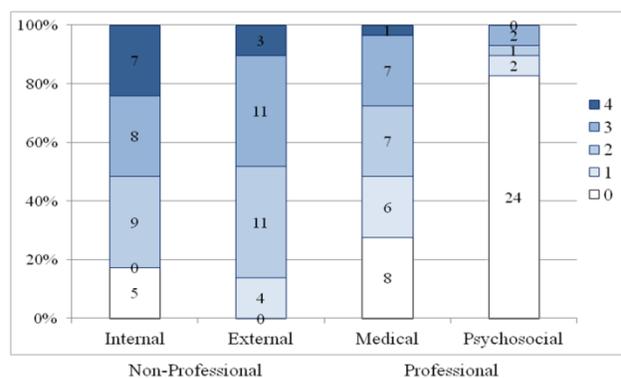


Figure 2. Frequency of each rating within each of the four psychosocial supporter categories.

showing 1 to 8 support characters in the category of external non-professional supports with 85 total identified among the 29 films. There was an average of 2.93 characters per film. The majority of the characters in this category were friends (49%). Of the 35 childhood cancer characters studied, 26% had a teacher shown, 20% had a significant other, and 14% had significant community involvement in providing support. Generally, there is a lack of emphasis on maintaining an educational curriculum, and very few films show patients receiving help through a home or hospital tutor.

Professional Support Characters

Films ranged from showing 0 to 11 support characters in the category of professional medical supports with a total of 54 identified in the 29 films. Compared to the non-professional support categories, the average number of professional medical support characters per film was found to be lower, at 1.86. The majority of characters in this category were oncologists (48%) followed by nurses (33%). No professional medical supports, and thus a limited treatment team, were found in over one-fourth of films (28%). One-third of films did not show an oncologist, and close to two-thirds did not show any nurses despite the significant involvement they have in the care of children with cancer. With regard to the professional psychosocial support category, films ranged from showing 0 to 5 support characters, but there were only 12 characters identified in total among the 29 films, with an average of 0.41 characters per film. Of the 12 characters shown, three were palliative care / hospice specialists, two hospital chaplains, two social workers, one psychologist, one mental health nurse, and two in the other category (counselor and the United Givers Foundation). Overall, only six films showed any professional psychosocial support services playing a role in the care of the pediatric cancer patient. Although 66% of patients in film passed away secondary to their cancer, only two films showed the presence of a palliative care or hospice specialist, and for only 11% of patients were palliative or comfort care measures used as part of treatment. The celluloid childhood cancer treatment team is thus generally scant, typically

represented by one main character rather than by a team, and is significantly devoid of any professional psychosocial support providers.

A more detailed analysis of the specific examples and images that emerged from this analysis of the types of psychosocial support provided to pediatric patients with cancer and their families on the screen will be outlined through the thematic concepts that emerged. Additionally, **Appendix C** provides detailed information on each psychosocial support character identified per film, their categorization into a supporter type, and their rating, and this was used to determine the overall ratings illustrated in **Table 8**.

E. Themes

Analysis of the 29 films generated seven themes in the celluloid pediatric cancer experience: disruption, social impact, psychological impact, physical toll, struggle/war/fight, coping, and barren landscape. Within each theme, subthemes were identified that further explored or categorized the overarching idea. The following analysis should serve to elucidate each theme through the lens of the films portraying that theme, and as a whole, will provide a comprehensive description of the pediatric cancer experience reflected by the cinematic mirror. A Primetime Emmy Award winning documentary following five children through their fight with cancer at Cincinnati Children's Hospital, *A Lion in the House* (2006), provides a unique, exceptionally intimate, and real view of the lives of pediatric cancer patients, their families, and their providers. Although editing of raw footage has potentially created a biased or less comprehensive depiction of the pediatric cancer experience, it nevertheless reflects most accurately current practices and will thus be used to describe each theme and serve as a backboard for understanding the Hollywood image reflected in the other 28 films. **Table 9** provides the schematic organization of the themes and subthemes and the number of films identified as containing each of the subthemes. For a more detailed picture of the themes and subthemes present in each film individually, see **Appendix D**.

Table 9. Themes Extracted from 29 Films with a Character with Childhood Cancer

Theme	Subtheme	# of Films	Films Illustrating the Theme
Disruption	Threat to a normal childhood	22 (75.9%)	<i>Ways to Live Forever, Declaration of</i>
	Change in living situation	15 (51.7%)	<i>War, My Sister's Keeper</i>
Social Impact	Isolation and alienation	22 (75.9%)	<i>Oscar and the Lady in Pink, Restless,</i>
	Families struggle alone	14 (48.3%)	<i>Hello Brother, Declaration of War</i>
Psychological Impact	Preoccupation with death	18 (62.1%)	<i>Ways to Live Forever, Restless,</i>
	Find meaning in life / mature	16 (55.2%)	<i>Swimming Upstream, Declaration of</i>
	Emotional distress	23 (79.3%)	<i>War, The Ultimate Gift</i>
Physical Toll	Physical changes / suffering	19 (65.5%)	<i>My Sister's Keeper, Oscar and the</i>
	Threat to self-esteem	10 (34.5%)	<i>Lady in Pink, One Last Thing</i>
Struggle/War/Fight	Parents fight till the end	8 (27.6%)	<i>Declaration of War, Desperate</i>
	Cancer care as a horror show	9 (31.0%)	<i>Measures, My Sister's Keeper, The</i>
	War against carcinogens	2 (6.9%)	<i>Haunting in Connecticut</i>
Coping	Reliance on religion and faith	12 (41.4%)	<i>Camino, Letters to God, Ways to Live</i>
	Parental coping	26 (89.9%)	<i>Forever, Hello Brother, A Walk to</i>
	Child coping	20 (69.0%)	<i>Remember, Restless</i>
Barren Landscape	Empty hospital environment	19 (65.5%)	<i>Declaration of War, The Darkest</i>
	No treatment team, limited	22 (75.9%)	<i>Light, My Sister's Keeper, Desperate</i>
	mental health providers		<i>Measures, Hello Brother</i>

Theme 1: Disruption

In *A Lion in the House* (2006), viewers are thrown into the pediatric cancer world, suddenly finding themselves within the walls of the oncology ward at Cincinnati Children's Hospital among the pediatric cancer patients, the lions of the movie. They experience and are awakened by the invasion of cancer as are the families depicted. Each of the five family's lives is disrupted by cancer as parents leave jobs to care for their sick child, previously stable families are shaken by the financial burden of expensive and long treatments, and both children and families

lose their independence. For example, Tim's strong and independent single mother, used to being able to care for everyone in her family, now must go on welfare and rely on cab vouchers to get her 15-year-old son with Hodgkin's lymphoma to his hospital appointments. After another relapse, she cries to the camera, "All I know is that he must be really tired of all of this. This is not what I pictured him doing when he was 15."¹² Justin's mother also talks about the disruption to his childhood that a 10-year battle with leukemia had for her now 19-year-old son, "Being sick, his age group got to move on and he's kind of stuck, didn't really move on. He never went to a senior dance, girls, driving, and [...] just hanging out with the guys."¹³ Hollywood film narrative, based on a foundation of contention, has consistently reflected this image of disruption. On the screen, cancer invades a child's body, threatens his/her innocence, growth, and rights of childhood, and wreaks havoc for families by rattling social, financial, and living situations. Two subthemes of disruption are particularly reproduced in the cinematic pediatric cancer experience:

"Normal childhood" is not for me: I now belong to the "cancer world"

In *Ways to Live Forever* (2010), 12-year-old Sam tells us that he has "colorless granular spiroidal globules"—leukemia that has relapsed twice leaving him with no treatment options. Highly mature for his age, Sam is concerned with understanding his illness, and the nuances of life and what it means to die, pondering questions other kids his age would never understand. Due to his illness, he has missed a considerable amount of school, and when the question of returning to school is brought up at the family dinner table, he insists on staying at home, afraid that other children would stare at him and question why he is able to leave school early when he is tired.¹⁴ There is a "normal world" and a "cancer world", with a clear divide in priorities and understanding between the inhabitants of each world. Normal childhood events, such as going to school, are disrupted and cannot, and possibly should not be re-incorporated. A home tutor who

¹² *A Lion in the House* (2006): Disc 1, 1:36:50-1:38:30 and Disc 2, 18:00-19:43.

¹³ *A Lion in the House* (2006): Disc 1, 16:00-16:49.

¹⁴ *Ways to Live Forever* (2010): 13:35-14:58.

encourages Sam to write about his experience and ponder questions about death, and a friendship with another teenage boy with cancer become the appropriate environment for Sam.

More than 75% of films viewed highlight this disruption to “normal childhood” that cancer brings. “Normal childhood” means receiving an education, having future potential, participating in childhood activities (sports, games), and having an innocence and immaturity. Eight-year-old Tyler in *Letters to God* (2010) has a bedroom full of soccer trophies, medals hanging on the walls, and posters of athletic heroes to signify this “normal childhood”. However, in the film narrative in which Tyler suffers from a terminal medulloblastoma, this image, rather than being uplifting, disheartens viewers. It serves as a constant reminder of the childhood that has been stolen from Tyler, who can no longer play soccer and will never be able to live up to his heroes. While a dress-up game in which he puts on silly, fake eyebrows to cover up his hair loss provides a glimpse into his childish nature, scenes like the one in which he maturely tells classmates who tease him about radiation—that it does not hurt but will affect his growth—reflect a Hollywood image of childhood cancer as an entity that forever removes children from the “normal childhood” world symbolized by Tyler’s room and his classmates.¹⁵ Viewers are taught that it is almost cruel to expect children with cancer to return to this world. Rather than fighting the disruption to their lives that cancer has brought, children with cancer in Hollywood may acknowledge and, at times, display anger toward the disruption, but are generally expected to accept their new role in the “cancer world”.

Cancer introduces cracks, but they only strengthen the foundation

The invasion of cancer not only disrupts the normal childhood experience, but also threatens normal family structures, roles, and lifestyles, depicted throughout contemporary films through scenes about financial stress, loss of employment typically for mothers, and changes in the social environment for parents. Having a child with cancer turns previously stable and successful families into fragile, cracked entities. This is summarized by the father of 15-year-old

¹⁵ *Letters to God* (2010): 27:40-28:48.

Kate who has acute promyelocytic leukemia in one of the most popular contemporary films about childhood cancer, *My Sister's Keeper* (2009). He tells the audience:

Having a child who is sick is a full-time occupation. Sure, we still enjoy the usual day-to-day happiness of family life—big house, great kids, beautiful wife—but beneath the exterior, there are cracks, resentments, alliances that threaten the very foundation of our lives...as if at any moment our whole world could come tumbling down.¹⁶

When Kate is diagnosed with cancer at a young age, Kate's mother leaves her job as a lawyer and devotes all of her time and energy to keeping Kate alive. Kate's aunt moves in with the family to help and care for Kate's brother, Jesse, and sister, Anna. Anna, herself, is a product of a decision by Kate's parents to have a child who would be a genetically engineered match to Kate for such things as bone marrow transplantation. Kate's cancer necessitated and defined the life the family was living, a life that was drastically different before Kate became ill.

While not as central to the film narrative in most cases, more than one-half of the films viewed portray some aspect of this disruption that childhood cancer brings to family lifestyle, most commonly depicted as new financial difficulties typically resulting from loss of employment for a parent, but also as changes in living situation and changes in parental social situation and lifestyle, each seen in one-fourth of films. In the French film, *Declaration of War* (2011), young parents, Romeo and Juliette, learn that their 18-month-old son Adam has an aggressive, malignant brain tumor. They immediately prepare for and stage a battle against the disease, and although their son survives, the victory comes at a price. The narrator tells the audience:

They continued like this for two years, put on a brave face. They had no choice. They did it for Adam, for themselves, but reality caught up with them. They stopped working, stopped seeing friends, they cut themselves off. They were exhausted, solitude caught up with them. They separated, got back together several times, then separated for good. They each started a new life, but would stay close to each other forever. They remained strong, destroyed for sure, but strong.

Film acknowledges the long, arduous process of childhood cancer treatment, exposing viewers to the hardships and lifestyle changes families must overcome. While their strength is tested at times to a point where viewers are concerned that it might be too overwhelming to overcome, families

¹⁶ *My Sister's Keeper* (2009): 5:10-5:35.

consistently find creative and courageous ways to deal with the disruption. Their lives may be changed by the cancer experience, but as was shown in the documentary, families' resilience prevails. While initially concerned, audiences are left satisfied by the increased strength and improved life perspective that the cancer experience has brought to the parents and families who have sacrificed for their children.

Theme 2: Social Impact

As described earlier, cinema creates a “cancer world” to which children with cancer and their families belong, which is distinct from the world of expected childhood experiences. This world unites those with childhood cancer through shared experiences and perspectives, and, at the same time, generates a cohesive paradigm for viewers about what it is like and what should be expected of a child with cancer. However, as described by many of the patients and families in *A Lion in the House* (2006), being a member of the “cancer world” makes one alien to those in the world of normal experiences. A typically outgoing child, Tim develops behavioral problems and issues with school attendance during his treatment. When confronted about this by his psychiatric nurse, Tim tells her, “Every school I’ve been to since I’ve had cancer has been horrible. I’m always by myself except for when I’m with my cousins. Always by myself,” and when he is asked if he thinks it is because of his illness, he tells her, “Yeah, they think I’m diseased because no one ever talks to me.”¹⁷ While Tim’s social life becomes limited, others, like seven-year-old Alex who has leukemia, are able to maintain some normalcy in their social interactions through efforts by the family and teachers to encourage school attendance and support from classmates. Nevertheless, whether due to long hospitalizations, general lack of time to include a social life, or frustration at the lack of understanding from others, children with cancer and their families are often isolated in the “cancer world”. Cinema consistently captures this isolation on the screen, perpetuating the image of an alienated, bald-headed child whom the audience and society pities, who is teased at school, who finds solidarity only in other sick children, and whose family

¹⁷ *A Lion in the House* (2006): Disc 1, 59:15-1:00:04.

struggles alone to survive the cancer. Siblings are often neglected in the struggle, highlighted by Justin's adult brother, Adam, in *A Lion in the House* (2006), whose depression is unrecognized by the rest of the family and whose opinions are infrequently heard.¹⁸ On the screen, Hollywood has captured many such images of frightened, confused, and neglected siblings. The following two sub-themes emerged on the screen regarding the social impact of pediatric cancer:

We're not cancer kids, we're kids with cancer

Given the importance of creating a memorable character identity on the screen, Hollywood aptly portrays children with cancer struggling to develop their own personal identity in the face of an illness that seems to define their character. In *Restless* (2011), Annabel is a teenage girl whose character is defined by someone who has a terminal brain tumor and three months to live. However, her character also has a strong and charming personality, a love for Darwinism and the natural world, and a growing relationship with Enoch, a boy recovering from the loss of his parents in a car accident. Annabel grapples with these two identities throughout the film, desiring to be seen for more than her illness. When Enoch asks her if the Webber Hospital is the hospital where all of the cancer kids live, she corrects him and tells him that they are kids with cancer. She adamantly makes this distinction throughout the film, which illustrates the interesting social dichotomy between a "cancer world" that serves as an environment in which some find themselves versus an identity that one is assigned. Annabel makes her "cancer world" the environment through which her personal identity as a curious, carefree, and slightly rebellious girl emerges, however, this is often not the case in Hollywood, where the "cancer world" as an identifier serves as a convenient social character label.

Oscar in the French film, *Oscar and the Lady in Pink* (2009), is a 10-year-old boy who receives such an identity, labeled as a cancer kid and living in an institution with other ill children. Although extreme in this case, where all of the sick children are physically isolated from the rest of society and even their parents in an institutional setting, the cancer identity frequently

¹⁸ *A Lion in the House* (2006): Disc 1, 37:45-38:53 and 45:18-45:51.

isolates children from their “normal” peers in an environment of preferential treatment, societal pity, and differences in appearance, seen in over three-fourths of the films. Oscar is lonely and frustrated by his cancer identity, which has alienated him from others who no longer see him as a playful child but rather as an ominous and tragic story. His parents have become “two idiots with no conversation,” and he tells Rose, the only person who is honest with him, “No one laughs anymore...they’re afraid of me.”¹⁹ Viewers’ own emotions are reflected in this statement, as audiences are frequently conflicted about how to respond to the cinematic presentation of a “cancer kid”, a bald-headed tragic hero. They are inclined to befriend the child, but this comes with the difficult demands of accepting the complexity of the cancer experience and the vulnerability of knowing that the child will die, demands which alienated the child in the first place in the film narrative.

A desire for characters with childhood cancer to be seen as more than just their cancer fundamentally reflects their desire to belong to their societies. When ten-year-old Johnny, dying of leukemia, returns to school for the first time in the film *Johnny* (2010), he is confronted with teasing—kids calling him “baldy”—and is physically hurt by two boys. To the audience, he is the vulnerable outsider thrown into an ignorant and cruel world. Yet, when he is told that it is okay if he no longer wishes to return to school, he replies, “Today is the first day I felt like a normal kid. I’m going back tomorrow, and every day after that.”²⁰ Here, the prevalent idea, seen in films like *Ways to Live Forever* (2010), that children in the “cancer world” should be protected and separated from the threats of the “normal childhood world” is challenged. Ten-year-old Billy in *Snowmen* (2010), who “used to have tons of friends back before [he] started getting sick all the time,” similarly fights bullying at school as part of his experience of returning to the normal childhood world after having recovered from cancer. When he tries to convince his classmates and himself that he no longer has cancer, a girl meanly yells at him, “Yeah, then take your hat

¹⁹ *Oscar and the Lady in Pink* (2009): 13:50-16:08 and 43:12-44:40.

²⁰ *Johnny* (2010): 37:28-39:00.

off?” Kids call him a “sick freak” and one girl tells her friend that she doesn’t want him to touch her.²¹ He, nevertheless, prevails and brings his school and community together in a mission to set a world record for number of snowmen built in one day. The celluloid image of social stigma and fear from peers toward children with cancer that is portrayed in one-fifth of the films, leaves viewers angry and ashamed of society’s ignorance. While *A Lion in the House* (2006) and *Letters to God* (2010) portray some involvement by teachers and the health care team to help children with cancer re-integrate into school and their social environment, in the majority of films, the children themselves possess a maturity and resilience that allows them to courageously stand up and overcome the social isolation, injustices, and bullying and become role models for other children and society. Audiences are inspired and uplifted by the children, who remain true to their identity as “cancer kids”, those with unwavering bravery and a positive attitude. Despite being alienated by their cancer and an ignorant society, these children persevere and, through their cancer experience, enlighten and unite their communities and audiences, restoring viewers’ faith in humanity and society.

Can do it alone

Like the portrayal of the social challenge that the cancer experience poses to children, film also reflects socially isolated families who are left alone to cope with the disruption that cancer brings to their lives. In the film narrative, the family is the focus, isolated in the cancer experience that either breaks or re-makes them. In *Declaration of War* (2011), parents Romeo and Juliette are broken apart by the isolation and emotional burden of the cancer experience, yet they forever stay united by the support they can provide to each other because of their unique understanding of the cancer world. Outside friends who show pity and ignorantly seek to find explanations for the cancer cannot be expected to provide such support. In *My Sister’s Keeper* (2009), the extended family comes to provide support to Kate when she is in the hospital, and the contrast between those who have direct experience as part of the “cancer world” and those

²¹ *Snowmen* (2010): 3:55-4:15 and 20:30-21:00.

outside it becomes shockingly apparent. The family tells Kate on her deathbed to “Keep fighting...a lot of living to do,” and advises her, “You’ve just gotta tell yourself you’re gonna get better. Tell your brain to heal yourself and work on it while you’re sleeping...The subconscious mind is a really powerful thing.” As the extended family’s excitement grows through their discussion about miracles and the power of the unknown beyond science and medicine, Kate and her immediate family solemnly sit in silence.²² The cancer experience has forever separated them not only from friends but from their own family, and it is up to them alone to cope with the experience. They are challenged by conflicting opinions toward pursuing treatment—a mom whose obsession with fighting the cancer has made her lose touch with reality, a father who has allowed himself to step back and see that the quality of Kate’s and their families lives together may be the more important goal, and two siblings engaged in a battle with the law to uphold their sister’s wishes to stop treatment. Yet, their common bond as members of the “cancer world” who understand the associated stressors brings them together. Alone and away from those who cannot possibly understand their experience whether in the hospital, at home, or on the beach, they are the happiest and most at peace. The cancer world may have isolated them from their friends and family, and challenged their family structure, but they, just as Romeo and Juliette and one-third of families in film, are forever united by the cancer experience.

Apart from parental discord about treatment goals frequently portrayed in film, one of the most pervasive challenges to family structure brought on by childhood cancer is sibling isolation and neglect, a topic dealt with in close to one-half of films with a character with childhood cancer. Sharing her scrapbook with audiences, Kate in *My Sister’s Keeper* (2009) reveals, “I don’t mind my disease killing me. But it’s killing my family too. While everyone was so worried about my blood counts, they barely even noticed that Jesse was dyslexic...Jesse, I’m sorry I took all the attention when you were the one who needed it the most.”²³ On the screen, audiences are

²² *My Sister’s Keeper* (2009): 1:29:18-1:32:00.

²³ *My Sister’s Keeper* (2009): 25:34-28:54.

exposed to and empathize with such images of overwhelmed parents with little outside support struggling to care for a sick child while maintaining some relationship with and normalcy for healthy siblings. Young siblings, desiring to remain included in the family, to share in their sibling's new experience, and to receive the attention they are used to, are excluded and left outside of the cancer world. The new changes are rarely explained to them, parents are unable to find time to address their unique needs, and they are even physically separated from their sibling by necessary infectious safety precautions. This conflict serves as the main narrative in the Korean film *Hello Brother* (2005), in which young Hani struggles to cope with and understand his 15-year-old brother HanByul's new life with a brain tumor. Feeling left out of HanByul's new hospital experience, worried and uncertain about what is happening to his brother, and faced with increased expectations from his parents to appease his brother, Hani is left conflicted by emotions of anger at his brother and fear for his brother's life. In a moment of frustration after HanByul and his mother yell at Hani to turn off the music he had been trying to use to cheer the mother up, Hani runs to the bathroom and rebelliously uses HanByul's towel to wipe his face. In a horrific scene following this, HanByul awakens with a high fever and is rushed to the hospital by concerned and overwhelmed parents who leave Hani at home by himself for the night.²⁴ Hani, staring with guilt at his brother's towel in the bathroom all night, serves as a potent image for viewers of the often-neglected emotions and experiences of siblings of patients with cancer. Such images of commotion surrounding the sick child with the sibling left alone to cope are abundant on the screen. Viewers see siblings as innocent bystanders to the childhood cancer experience, an unfortunate result of families who now have too much to handle and whose priorities must thus change. There is little hope in film that the social impact of childhood cancer described in this section can be avoided, and audiences thus continue to marvel at the strong patients, families, and siblings who prevail despite this on the screen.

²⁴ *Hello Brother* (2005): 26:45-32:00.

Theme 3: Psychological Impact

The threat to life for a child, the distressing and toxic treatments, the constant uncertainty in outcomes, and the disruption and social impact already described leave a strong imprint on the psyche of pediatric cancer patients and their families; this psychological influence and the character development it allows has been of particular interest to filmmakers. While at times exaggerated and simplified, modern cinematic images of psychological distress and growth through the cancer experience are founded on a very real image portrayed in *A Lion in the House* (2006). After learning that he has relapsed again, 15-year-old Tim tells the camera, “When I’m bored, I think about stuff that I shouldn’t be thinking about, or I should be, but I don’t like to.” He describes going out and drinking alcohol with friends as an escape from these “bad” thoughts—“It’s better than staying at home crying.”²⁵ This psychological distress of the cancer experience is also evident for 11-year-old, typically free-spirited and humorous Al, diagnosed with Non-Hodgkin’s lymphoma, who is shown fearfully awaiting the results of his post-treatment scans. In the CT scanner, tears pour out of his eyes as he attempts to stay still; his chubby, childish face is now fraught with worry and ages before the viewer’s eyes.²⁶ The psychological distress and fear is a particularly unwelcome experience for innocent children, but is also overwhelming for parents and families. Alex’s mother tells viewers, “I just went to the doctor and I told him I don’t know what’s wrong with me, I feel like I’m losing it... Trying to get through everything took its toll on me, took its toll.”²⁷ Such images of emotional and psychological stress caused by the childhood cancer experience are frequently dramatized on the Hollywood screen, and are particularly moving for audiences. Both in *A Lion in the House* (2006) and in fictional film, these psychological challenges lead to growth and maturity for patients and families, generating new meaning in their lives, although the Hollywood image oversimplifies the complex long-term

²⁵ *A Lion in the House* (2006): Disc 2, 1:02:20-1:03:15.

²⁶ *A Lion in the House* (2006): Disc 2, 1:12:40-1:15:00.

²⁷ *A Lion in the House* (2006): Disc 1, 56:49-58:11.

effects. Three subthemes serve to paint the Hollywood picture of the psychological impact of pediatric cancer:

Why does God make children get ill?

Children's innocence is founded in their freedom from knowledge of cruelty, of illness, and particularly of death. The cancer experience forces innocent children to confront these issues, and film exposes this through narratives about children engrossed in and preoccupied with death, seen in over 60% of the films viewed. *Ways to Live Forever* (2010) follows the experience of 12-year old Sam, who is generally curious about facts, and since facing terminal leukemia, facts about dying. As he makes a video diary of his life, audiences explore death through the eyes of a young child. His curiosity and questions expose his maturity: "How do you know when you have died? Why does God make children get ill? Does it hurt to die? What does a dead person look like or feel like? Why do people have to die? Where do you go after you die? Will the world still be here when I'm gone?" His mission to find answers to his questions is both endearing and heartbreaking. He learns what a dead person looks and feels like by standing over his best friend, Felix's body, who had passed away from cancer: "It was him, but he was stiff and sleeping and cleaner than in real life. He was cold like the coldness of statues. I'd been hoping they had made a mistake but they hadn't, Felix was empty."²⁸ Just like his father who "doesn't like to answer [his] kind of questions," audiences hopelessly desire to protect Sam's innocence from these sinister subjects. Yet, it is the open and honest confrontation of these topics by Sam's parents and audiences, just like his home tutor, that eases the psychological turmoil a lack of understanding and knowledge caused Sam. Similarly, in *Restless* (2011), 16-year-old Annabel develops an obsession with planning for her death, enacting multiple death scenes with her boyfriend Enoch to prepare for the final event.²⁹ In this way, cinema exposes viewers to children who want to talk about their illness and about death, who suffer psychologically when they are unable to do so, and

²⁸ *Ways to Live Forever* (2010): 57:44-1:00:54.

²⁹ *Restless* (2011): 59:10-1:03:18.

who have the maturity necessary to understand what will happen to them. They are preoccupied by what it means to die and why it is happening to them, thoughts that dictate their identity, development and actions. Cinema willingly follows this journey, exposing, especially teenage children with cancer, questioning and rebelling against their illness, engaging in risky behaviors, changing the way in which they live their lives and form relationships with others, and in the process, growing into mature adults devoid of their innocence but with an impeccable understanding of illness and death.

Damned fish swimming upstream against the current

Seventeen-year-old Morris's psychological journey of coping with the diagnosis of chronic myelogenous leukemia in *Swimming Upstream* (2002) portrays this ability of cancer to serve as a maturing agent, teaching children and their families about the meaning of life and the importance of leaving something behind. Feeling doomed to die, Morris struggles to comply with the new treatments and lifestyle changes. When confronted about this by his oncologist, Morris tells him, "I'm scared and I want the scared thing to go away. I want to live every last minute I can you know. I feel like a damned fish swimming upstream against the current, being pushed back, unable to reach where I'm going, like my life is compressed."³⁰ These feelings of lack of time and desire to complete a mission before one dies permeate the Hollywood childhood cancer experience. In *Johnny* (2010), ten-year-old Johnny with leukemia seeks to find a family before he dies, and his illness and death help his oncologist's family—who adopt him—cope with the loss of their own son in a car accident. In *The Ultimate Gift* (2006), 12-year-old Emily also dying of leukemia, befriends a spoiled, trust-fund baby seeking to obtain his grandfather's inheritance, and teaches him about the true meaning of wealth and happiness, epitomized by her dream for "a perfect day," a day which she spends with the people she loves and they are all happy. Her effects on his life and the community are immortalized in "Emily's Home," a place he opens after Emily dies, where families can live during cancer treatment. The compressed lives of characters with

³⁰ *Swimming Upstream* (2002): 1:01:14-1:06:28.

childhood cancer, which are spent in a constant battle against the current of cancer, seem to color their lives with special meaning, a special understanding about the quality of life as more important than the quantity. In this context, the childhood cancer characters mature on the screen. Morris tells us, “I’m thinking my life changed long before I wanted it to. Yesterday I was a 17-year-old kid and today I’m suddenly older.” This ability of cancer to generate meaning in life and for children with cancer to leave lasting impacts on those around them is seen in over one-half of the films, but it is not the whole cinematic story. While most children fight to be more than “damned fish,” for their journey against the current to mean something, some films challenge viewers with the notion that there may be no special meaning in a child’s illness and death. Anna in *My Sister’s Keeper* (2009) tells audiences after her sister’s death from cancer:

I wish I could tell you that there was some good that came out of it, that through Kate’s death we could all go on living. Or even that her life had some special meaning like they named a park after her, or a street, or that the Supreme Court changed a law because of her, but none of that happened. She’s just gone, a little piece of blue sky now. And we all have to move on.

Just like cinema reveals the psychological struggle of childhood cancer patients to understand their illness and death, it also leaves viewers to reflect on and develop their own beliefs about the meaning of the pediatric cancer experience.

We’ve been wrung out like in a washing machine

Whether or not the childhood cancer experience brings special meaning to the lives of the child and family, Hollywood consistently reflects the emotional toll that the experience has on families, who, as Al’s mother in *A Lion in the House* (2006) poetically illustrates, have “been wrung out like in a washing machine” by the cancer experience. Seen in close to 80% of films with a character with childhood cancer, the psychological distress associated with the fear of death for a child and the anticipatory grief involved, leave the family emotionally overwhelmed. In the UK film *The Darkest Light* (1999), the parents of eight-year-old Matthew, suffering from leukemia, sit at the dinner table reflecting on his sister feeling left out and Matthew being scared, which, according to the mom, “is all just too much to deal with.” When the mom asks the father,

“Do you ever think about it, if it doesn’t work out, the treatment,” they both just pour alcohol in their drinks.³¹ Alcohol later becomes a problem for the father, a necessity to dull the emotional burden of persistently worrying about his child’s life. In *Katie’s Wish* (2007), 13-year-old Katie, diagnosed with leukemia at six years of age, has lost her mother, who left the family after Katie’s diagnosis because she could not take care of Katie, could not “deal with this.” Abandoned by the mother, Katie’s father devotes his life to caring for her and remaining emotionally strong, but he does admit, “It was hard for me you know, watching her sick all the time, going through all those treatments, losing her hair. Every night, I go to bed thanking God that I had another day with her, and every morning I wake up and just ask to let today not be the day.”³² The celluloid cancer experience is based on the frightening foundation stated outright in *A Civil Action* (1998)—a film that recounts a court case over a contaminated, carcinogenic water source—that “Anybody with a disease like leukemia could die any minute.” This uncertainty inherent in the childhood cancer experience combined with the distress associated with a toxic treatment process and the threat to life for a child is used by Hollywood both to reflect the emotional toll of the childhood cancer experience for families as well as to arouse in audiences the same emotional experience.

Theme 4: Physical Toll

The physical effects, particularly pronounced on a child, of the cancer itself and, even more so, the treatment process, form the essence of what it means to be sick with cancer on the screen. In *A Lion in the House* (2006), viewers are shaken by images of 15-year-old Tim vomiting over himself as a nasogastric tube is passed down his nose.³³ Nurses tell the camera, “Tim has his image to uphold. He doesn’t want to walk around with that,” and “It is very difficult for a teenager to go through that, putting a feeding tube down them and having to deal with that on a daily basis.” However, it is the tears that begin to flow, transforming Tim’s typically brave and thoughtful face to one that is afraid, embarrassed, and shocked, that leave a potent and lasting

³¹ *The Darkest Light* (1999): 44:15-44:51.

³² *Katie’s Wish* (2007): 49:00-51:30.

³³ *A Lion in the House* (2006): Disc 1, 41:30-44:00.

image for viewers of the horrific emotional and psychological effects of procedures and the cancer treatment process. Similar images of 19-year-old Justin, who embodied the fighting spirit and refused to quit, now paralyzed and bed-bound due to a stroke, and previously active and playful Alex, exhausted in bed, crying and begging for water before her surgery for a disfiguring fungal infection appall audiences, but create a clear image for what it is like to be a child with cancer. In fictional cinema, these honest, intimate images of physical suffering seen in *A Lion in the House* (2006), would overwhelm the narrative and audiences, and have thus been replaced with a Hollywood image of a sick child. While this image is simplified and beautified for the screen, it still attempts to reflect the physical toll of cancer and treatment, and its emotional and psychological effects as seen in the following two subthemes:

I am bald, therefore, I suffer

On the screen, the discourse surrounding physical symptoms and changes in personal image brought about by the cancer experience surpass the visual presentation in which most childhood cancer characters maintain their weight, strength, and functionality for the purpose of the narrative until close to the film's end, at which point little of their final suffering is shown. Hair loss, one of the most common and well-known effects of cancer treatment, thus becomes a fairly tolerable image for viewers to signify the physical impact of cancer throughout the film without overwhelming audiences. On the screen, a child with a bald head is the essence of what it means to be sick with cancer, the symbol for illness and physical suffering. In a horrific scene in *The Darkest Light* (1999), Matthew begins to pull out his hair in chunks at the dinner table, and is paralyzed by fear. His father drags him to the backyard, holds him down, and shaves his head like shearing a sheep without uttering a word as Matthew cries.³⁴ In this way, through film, audiences learn to associate the loss of hair with the pain and suffering of the childhood cancer experience.

The discourse surrounding the physical toll on children focuses on concepts of pain, fatigue, and weakness preventing participation in activities that were meaningful to the child, a

³⁴ *The Darkest Light* (1999): 25:55-28:17.

concept summarized by the eponymous character in *Johnny* (2010): “The spirit is willing, but the flesh is weak.” While the occasional film shows images of pain, like the horror film *The Haunting in Connecticut* (2009), which shows 16-year-old Matthew with a terminal cancer writhing around and sweating from generalized pain after his radiation treatment³⁵, in most films, audiences are told about the pain but infrequently see what it means to be in pain. Additional occasional images of nosebleeds, vomiting, coughing, and exhaustion provide a glimpse of the cancer experience for audiences, but their brevity and the quick return to normalcy for children suggests a temporary nature to the suffering, which comforts audiences. After an episode of incontinence, Anna helps to clean up her sister Kate in *My Sister’s Keeper* (2009), and Kate tells her, “Don’t worry. It’s just the new medicine getting ready for the kidney.” When Anna asks her if she is in pain, Kate replies, “My whole life is a pain. This is the end, sissy. It just gets scarier from here on out. Mom’s gonna chop me and cut me till I’m a vegetable. Two cells in a Petri dish that she shocks with an electric cord.”³⁶ While the discourse suggests the horror of the cancer treatment experience, audiences appropriately are not required to bear witness to this experience as Kate remains alert and composed, although a bit weak, until the moment that the audience learns that she has passed peacefully overnight. In this way, cinema taunts audiences with what it may be like for a child to have cancer—the child who can no longer pursue her dream to dance, the weak and pale child lying in bed with slightly labored breathing, and the child who removes his hat to show a bald head—but consistently “protects” viewers from the full exposure seen in *A Lion in the House* (2006).

She’d have to like aliens

Cinema may have stayed away from full exposure to the “sick child”, but it consistently confronts the threat to self-esteem that the physical symptoms and changes in personal image associated with the cancer experience bring. The ten-year-old lead in *Oscar and the Lady in Pink*

³⁵ *The Haunting in Connecticut* (2009): 7:27-8:30.

³⁶ *My Sister’s Keeper* (2009): 1:24:25-1:26:15.

(2009) explains to his confidante, Rose, why no one laughs around him anymore, “Maybe because I’m not a good patient, the kind who makes them happy, gives them faith in medicine. Yet, I never complain when it hurts.”³⁷ Throughout the cancer treatment process on the screen, children are rewarded for completing procedures, for improvements in blood counts, for good response to treatments, and their self-esteem thus becomes delicately intertwined with their medical progress. A poor response to treatment, worsening symptoms, or rejection of a bone marrow transplant become personal failures for children—they have somehow behaved badly.

This is in addition to the threat to self-esteem that is inherent in the typically negative physical changes these children experience. When Rose encourages Oscar to talk with his crush, Peggy Blue, a girl waiting for a cardiac operation, Oscar tells Rose, “She’d have to like aliens and I doubt she does.” The physical changes associated with cancer, particularly hair loss, uniquely alienate children with cancer from not just “normal” children but also other sick children. Whether it is the shock of the sudden and unpreventable change in appearance for the child himself, teasing from other children, or a general feeling of being different, there is an inherent embarrassment that lowers self-esteem among children with cancer who have lost their hair. This is particularly tough for adolescent patients, reflected in *My Sister’s Keeper* (2009), in which Kate grapples to accept her physical appearance, refusing to leave her bed because she is “ugly” and sadly attempting to commit suicide in a horrific scene in which her sister finds her alone in her room drunk with an empty bottle of pills.³⁸ Having cancer makes children feel somehow defective, and this dominates their self-image. By shaving her own head, Kate’s mom helps Kate dissociate her outward appearance from her inner identity—being bald is not being defective—and boosts her self-esteem. In film narrative, the child’s “spirit” and the strength of those closest to the child prove enough to overcome the threat to self-esteem inherent in the cancer experience.

³⁷ *Oscar and the Lady in Pink* (2009): 13:56-15:10.

³⁸ *My Sister’s Keeper* (2009): 12:30-13:00 and 23:35-24:31.

Theme 5: Struggle/War/Fight

As one of the most dramatic aspects of the pediatric cancer experience, the struggle against death drives the illness narrative on the screen. With the diagnosis of cancer, a battle ensues between the evil cancer and the good and innocent child with parents frequently consumed by their role as commanders of the “good” side. The theme of struggle permeates the illness narratives of the five patients in *A Lion in the House* (2006). Justin adamantly portrayed the fighting spirit through much of his cancer experience, and his parents subsequently struggle to transition to end-of-life planning after his stroke. The father unwillingly participates in what he calls the “doomsday meeting,” the team meeting called to discuss treatment goals, and the mother tells the camera after, “They’re not really focusing on leukemia at this point, but just, you know, what’s going on with his life. But I’m still focusing on leukemia. I’ve been fighting for 10 years and I just feel like I still need to be in focus with that.”³⁹ When six-year-old Jen completes her treatment protocol for leukemia, her parents are unsatisfied with the success. Before, they were doing everything to fight the leukemia, and now they would be doing nothing and there would still be an 8% chance of relapse.⁴⁰ Her mother thus continues to fight by running in a fundraising marathon for cancer research. The children themselves are portrayed as soldiers in the battle. When eleven-year-old Al reflects on the time of his diagnosis, he says, “It felt like I was going to live or die, and I had to fight it.” The Hollywood screen consistently captures and reflects images of this struggle against death and the war against cancer through the following three subthemes:

In the war against cancer, leave no stone unturned

While war metaphors are plentiful in the celluloid childhood cancer experience, the image is most clearly presented in the French film whose title epitomizes the theme, *Declaration of War* (2011). After learning that their 18-month-old son has a very aggressive type of brain

³⁹ *A Lion in the House* (2006): Disc 1, 1:04:37-1:06:26.

⁴⁰ *A Lion in the House* (2006): Disc 2, 55:35-56:39.

tumor, the parents devise a plan of attack, and begin training and execution. As they present their plan to the medical team, images of them jogging increasingly in unison are intertwined:

All we can do is foster his development. We'll take things day by day. We'll get government aid to help take care of him. We'll have quality time with him in the afternoon, it's healthier, or we'll never keep this up. We'll take daily notes and share them with you. If our parents ask about Adam don't bother answering, especially my mom. Not to keep her in the dark, but she panics and imagines the worst, and it gets us nowhere.

When the doctor reminds them that there will be another level and that they'll have to be strong, the parents' work-outs become even more strenuous.⁴¹ Only through strict military-like discipline, focused preparation, and unwavering devotion to the plan of attack can Romeo and Juliette conquer the chaotic hospital environment, the projected 10% survival rate for their son's tumor, and the arduous multi-year treatment process. Although there are losses along the way—the loss of their marriage, the loss of friends—they are united in their side of the war and ultimately come out victorious.

In the context of a war, parents are prepared to do whatever it takes to ensure that their child survives; dramatic interventions and outcomes thus dominate the screen. A particularly exciting narrative in this context is the dramatic search to find a bone marrow donor for a dying child, a common story seen from the earliest childhood cancer movies. In the thriller *Desperate Measures* (1998), a police officer, Frank, takes extreme measures, even breaking the law, to capture a serial killer, McCabe, who is the only potential bone marrow donor for Frank's nine-year-old son suffering with leukemia. When McCabe escapes from the operating room, Frank, joined by the courageous oncologist, Dr. Hawkins, risks the lives of fellow police officers, hospital personnel, and innocent passersby in his attempt to bring McCabe down alive. Even when the police chief confronts Frank, "How many people are going to have to die so that your son can live?" Frank is undeterred from his quest to save his son's life. In a statement that reflects

⁴¹ *Declaration of War* (2011): 1:05:08-1:06:00.

the celluloid childhood cancer parent—a resolute and self-sacrificing force—Frank declares, “Don’t presume to know what I’m prepared to do.”

While audiences root for parents like Frank and revel in his success at obtaining a bone marrow donation for his son, they are also forced to question the parent who has become so consumed in her courageous fight that the child’s perspective is lost in the process. In *My Sister’s Keeper* (2009), audiences marvel at Kate’s mother, Sara’s, strength and devotion to leaving no stone unturned to keep Kate alive. However, they learn the detrimental effects this can have on a child attempting to cope with and accept death. During the trial to determine Kate’s sister, Ana’s rights to refuse kidney donation, Sara interrogates Ana about her decision, and her brother finally reveals, “God, you people are so stupid! Kate wants to die! She’s making Ana do all of this because she knows she’s not gonna survive.” When Sara tells him that it is a lie, he continues, “Oh no, it’s not. Kate’s dying and everybody knows it. You just love her so much that you don’t want to let her go. But it’s time, mom. Kate’s ready.” Sara’s sister similarly confronts her about her obsession for fighting for Kate’s life and whether Sara is doing it for Kate or for herself:

I’m behind you no matter what. I’ll do whatever, and I do. I’m just not sure if you’re seeing the big picture. I know it’s important for you to feel like you never gave up. I mean who are you if you’re not this crazy bitch mother fighting for her kid’s life, right? But there’s, like, a whole world out there. You don’t see any of it, nothing. Sooner or later, you gotta stop. You gotta let go.

Sara dismally tells her, “I can’t.”⁴² In a rare moment on the screen, audiences are privy to not only the outward fight that childhood cancer parents put on against the cancer itself, but to the inner struggle they experience between trying every last option no matter how physically, emotionally, or psychologically exhausting to save their child versus conceding defeat and accepting the loss of their child. Kate acknowledges her mother’s fight, “You gave up everything for me: your work, your marriage, your entire life just to fight my battles for me every single day. I’m sorry *you* couldn’t win,” but shows audiences that while there is a fight against death that the mother lost, Kate engaged in and won her own battle to live and accept her life.

⁴² *My Sister’s Keeper* (2009): 1:20:24-1:23:54 and 1:04:45-1:05:35.

Good vs. evil: cancer care as a horror show

Although rarely questioning the necessity of treatment itself, close to one-third of the films portray the cancer treatment experience as a horror show: children enduring painful and toxic procedures and therapies from lumbar punctures in empty, dark, and sterile rooms to bloody and exposing surgeries to frightening radiation sessions that leave the child in pain. The childhood cancer experience can be as horrific as to serve as the backdrop for a horror film, *The Haunting in Connecticut* (2009), which focuses on sixteen-year-old Matthew, who has terminal cancer. He begins to receive a dangerous experimental treatment protocol at a hospital in Connecticut, which includes multiple rounds of radiation that leave him in constant pain, writhing around and unable to be touched by anyone. The doctor explains to his mom, “Well that’s his cells dying and being born again. Basically, we’re waging war in Matt’s body, and the battle’s just begun.”⁴³ For convenience, the family moves into an old house—converted funeral home—that is closer to the hospital, and Matthew begins to experience unusual visions and nightmares. Possibly losing his opportunity to receive the experimental treatment if he confesses to experiencing visual hallucinations, Matthew hides them from his family and physician. As Matthew’s illness worsens, the images become darker and more dangerous. Rather than a side effect from his treatment, the film suggests that the images are those of an evil entity that has been trapped in the house. Matthew is the only one who is able to see this entity and to be seen by it because of his special place between the worlds of the living and the dead. Other films, like *C Me Dance* (2009) and the Spanish Goya award-winning film *Camino* (2008), similarly suggest that children with cancer inhabit the liminal domain between the world of the living and that of the dead. In these films, the fight of a pure, innocent, young girl suffering from cancer in this domain against “evil” forces—the world of those without faith—is exploited for religious purposes. The horror of the child’s experience in this case is meant to reflect their self-sacrificing suffering for the betterment of society as a whole.

⁴³ *The Haunting in Connecticut* (2009): 5:50-6:39 and 43:30-44:25.

War against carcinogens and the large corporations that produce them

Cinema not only reflects the battle against cancer for individual patients and families, but also, as portrayed by the films *A Civil Action* (1998) and *Erin Brokovich* (2000), the war against large corporations whose production of toxic waste has led to outbreaks of childhood leukemia and other cancers in small communities. These narratives take advantage of society's growing fear and obsession with carcinogens, as well as their resentment of dishonest and self-interested large companies to engage audiences in the battle. Struggling to have their voices heard, the poor families of the children who have been affected are tormented by cold-hearted lawyers with little compassion for the parents who must re-live their child's illness and death through the trial. In *Erin Brokovich* (2000), a lawyer asks the parents of a 10-year-old girl suffering from a brainstem tumor, "Now if you could walk me through all the elements of Annabel's illness, specific details, when the symptoms began, prior to the first medical visit. If you could reserve sentimental embellishments I'd appreciate it. They're not gonna help you in court. I just need facts, dates, times."⁴⁴ The lawyer's and company's focus on money as the ultimate goal further deprecates these families' fight for change and for their children's health. In *A Civil Action* (1998), at the end of the case, the lawyer Jan presents the final settlement amount to the families, but cannot tell them that their community would be cleaned up. The mother of a child who had died tells him, "I wasn't interested in the money, just an apology from someone for what they did to my son. You told me that they apologize with money so would you call this an apology?" When Jan tells her that the only apology she would get is from him and that he's lost everything trying this case, she tells him, "That is not meaningful. How can you even compare what you've lost to what I've lost?"⁴⁵ Audiences are angered at a society that allows the private sector to threaten the health of its citizens, particularly the health of innocent, powerless children, and empathizes with the families for whom no amount of money can replace the child they have lost. Although in both

⁴⁴ *Erin Brokovich* (2000): 1:03:06 or 1:03:40.

⁴⁵ *A Civil Action* (1998): 1:31:00-1:32:58.

films, the communities win their respective battles against the large companies who are eventually punished and forced to institute cleanup projects, audiences are left fearful that they are hopelessly enlisted in a large war waged against an increasingly carcinogen-producing, careless, and apathetic industry.

Theme 6: Coping

As a mirror reflecting the childhood cancer experience, cinema has exposed a breadth of psychosocial concerns that drive the illness narrative. Through these psychosocial concerns, a theme of coping emerges, in which cinema plays with a variety of strategies utilized by childhood cancer patients and their families to understand and tackle the cancer experience. *A Lion in the House* (2006) presents many of these coping strategies as each family uniquely handles the cancer experience. Religion plays a role in several of the accounts. When asked about her thoughts regarding Tim's relapse, his mother explains to the camera, "I don't believe in odds. Odds are for people without faith, and I have faith." Although the families at times question God, faith consistently provides hope for the families, and serves as a means of comprehending and accepting the child's passing. For parents, other sources of coping include denial—Justin's father consistently refuses to address end-of-life care and decision-making to avoid confronting the possibility of his son dying, and Tim's mom struggles to come to the hospital to be with her son at the end of life—as well as an unwavering belief in specialist medical treatment exhibited by Alex's dad's fight for every last treatment option.⁴⁶ For the children, particularly adolescents, humor frequently serves as a coping mechanism. When Justin refuses to consider making a living will, he jokes with his parents that, "This way, if I don't, there is no way you can pull the plug."⁴⁷ Although grounded in these real and intimate emotional tools through which patients and families tackle the overwhelming psychosocial stress brought about by having a child with cancer, fictional film tends to exaggerate the coping process, creating a caricature that is often exploited

⁴⁶ *A Lion in the House* (2006): Justin's father, Disc 1, 1:04:37-1:06:08 and 1:18:40-1:20:23; Tim's mother, Disc 2, 1:27:30-1:36:18; Alex's father, Disc 2, 30:30-31:17.

⁴⁷ *A Lion in the House* (2006): Disc 1, 16:00-16:49.

to emotionally engage audiences. In this way, Hollywood depends on its images of coping to fuel an illness narrative driven by the psychosocial domain of the cancer experience. This is reflected in the following three subthemes:

In God we Trust

As the childhood cancer experience threatens an innocent, young child with the possibility of death, coping frequently relies on the religious domain, which attempts to comprehend the meaning of life and death. A little over 40% of the films examine this role of religion or faith in the cancer experience. Rather than presenting a clear role, films like *Oscar and the Lady in Pink* (2009) intend to generate discussion among audiences through the character's own maturing understanding. After his girlfriend Peggy Blue is taken to surgery, Oscar yells at Rose, "How dare your God allow this, such sickness, unless he's mean and incompetent?" Rose tells him that death is not a punishment but a part of life, and talks to him about finding the courage to accept death.⁴⁸ Rose utilizes concepts from religion to allow Oscar to open up about his emotions through the letters she encourages him to send to God as well as through discussions about physical and mental suffering and what it means to live a full life and die. A previously convenient target of anger for Oscar, Rose transforms religion into a coping tool for him to understand the value of his life as well as to cope with his suffering.

In other films, the cancer experience challenges the characters' underlying faith, and although moments of weakness and questioning are presented, almost uniformly the trust in God prevails to help families accept and find meaning in the child's illness and death. In the Christian film *Letters to God* (2010), eight-year-old Tyler is dying of a brain tumor and his typically strong and positive mother becomes overwhelmed by the fear of losing him. She cries to her own mother that she does not agree with God's will: "I have a little boy who is dying. Do you think he cares about God's will? I don't think God cares about any of this." Tyler's own faith, however, never wavers. He continues to write to God, to trust in God's plan for him, and in this way, inspires his

⁴⁸ *Oscar and the Lady in Pink* (2009): 57:20-58:15 and 1:01:20-1:03:30.

whole community. Dying at home, his family tells him that God cannot wait to see him and that it is okay for him to let go.⁴⁹ Tyler's enduring belief in God allowed not only himself but his whole family to cope with and accept his passing. Rather than stimulating thought and discussion about death and the complexity of the cancer illness experience, these cinematic narratives indoctrinate audiences with the idea that religion is equal to courage and bravery. Those with a trust in God are those with the fortitude to accept the cancer experience and be at peace with a child's passing.

The Spanish film *Camino* (2008) exposes this indoctrination through the story, based in real facts, of a 14-year-old girl's, Camino's, journey to sainthood through her ordeal with spinal cancer. Her often painful and arduous treatment process is exploited by the Opus Dei organization as a valiant and voluntary sacrifice—she suffers for Jesus. While Camino's dreams and discussions with her father, struggling to protect her from efforts at canonization, suggest that the Jesus with whom Camino so longingly wants to be is a teenage boy on whom she has a crush rather than Jesus Christ, religion becomes so intertwined in her treatment that she is caused significant distress and fear. Her devout mother, convinced that her daughter has been given an important and unique opportunity to bear a divine burden, suppresses her grief and almost inhumanely encourages her daughter's suffering. When a nurse tells Camino that it is okay if the IV insertion hurts her, Camino's mother coldly claims, "Nonsense. You have to be up to what the Lord expects of you." As Camino whimpers in pain, her mother tells her, "Try harder. You know how brave you can be."⁵⁰ Camino's sister is unable to provide support, kept away from Camino by the Opus Dei as part of her own sacrifice to Jesus. Even the hospital staff and the physicians taking care of Camino acquiesce to her exploitation for the Opus Dei. Physical symptoms, such as the loss of her eyesight and vivid dreams and hallucinations suggesting a delirious state are viewed by Camino's treatment team as divine communications from the Christ and the devil. In such a context, the role for end-of-life symptom management sadly vanishes, and she is left to

⁴⁹ *Letters to God* (2010): 1:00:55-1:02:34 and 1:39:30-1:40:30.

⁵⁰ *Camino* (2008): 1:11:28-1:12:01.

suffer. Her death becomes a spectacle, a highly anticipated event by all of the physicians, nurses, priests, hospital staff, and even family, who stand around her bed clapping in admiration as she passes away, unable to be with her crush, the teenage Jesus.⁵¹ Religion, particularly faith, as a means of coping with the cancer experience is here abused by an organization concerned with its self-image. Audiences are forced to consider whether other cinematic images of religion in the cancer experience serve a similar purpose.

Each day I cry in his place

When it comes to coping with a child's life-threatening illness, a particularly potent image is that of parents grieving. On the screen, scenes of a parent overwhelmed by the cancer experience sitting alone in anguish, arouse compassion in audiences, and are found in over 80% of films with a character with childhood cancer. Whether it is a mother in the Korean film *Hello Brother* (2005) submerging her head in cold water to numb her emotions and cover up the swelling from her perpetual crying, or a mother in the French film *Declaration of War* (2011), curled up alone on the bare hospital floor in shock after her son's diagnosis, or the father in the US film *Looking for an Echo* (1999), sitting by his daughter's bed, holding her hand, and singing to her on Thanksgiving night, cinema emphasizes parental grieving in the childhood cancer experience.⁵² Through concepts of denial, guilt, and anger, parents express their grief in cinema. In *Hello Brother* (2005), after HanByul's diagnosis of a brain tumor, the mother can barely look her husband in the eye, filled with guilt that she did not recognize HanByul's illness earlier: "I'm always snapping at him for throwing up in the car, whipping him for skipping academy classes, accusing him of lying. What did you do then?"⁵³ More commonly on the screen, seen in up to one-fifth of films, parents turn to avoidance as a mechanism to cope with the fear and grief of having a sick child. In *Ways to Live Forever* (2010), Sam's father struggles to talk about his son's

⁵¹ *Camino* (2008): 2:01:14-2:10:38.

⁵² *Hello Brother* (2005): 38:35-40:30; *Declaration of War* (2011): 30:20-32:30; *Looking for an Echo* (1999): 43:26-45:57.

⁵³ *Hello Brother* (2005): 14:00-15:30.

illness, coughing and saying “we don’t have to talk about that,” each time it is brought up. Sam, however, yearns to discuss his illness and death with his father, who Sam tells the audience believes that if Sam acts like a normal child, he will be cured. Here, and in most films, the denial catches up to the parents, who realize the distress they have caused their children by avoiding their illness, and thus avoiding the child himself. Sam’s father eventually joins Sam in helping him to achieve his “bucket list” and complete his memoir, and the audience sees that although confronting the grief can be a painful moment, it creates meaningful bonds between the parent and child.⁵⁴ Close to one-fourth of the films similarly show a child who has developed a mature understanding of his or her illness, providing support and encouragement to the parent to similarly accept and face the cancer experience. Audiences are soothed by the fact that although almost all films show parents grieving through the cancer process, almost uniformly parents find, through internal strength and a strong bond with their child, ways to accept and come to terms with the final outcome. The celluloid cancer experience leaves audiences with full faith in the parents’ overall comfort and strength to move on, and rarely exposes them to the coping required after, particularly for families dealing with the loss of a child.

Children courageously cope and are saved by love

While parents are often shown in distress and struggling to cope with the cancer experience, childhood cancer characters are presented as much more resilient, brave, and inquisitive toward their illness. Their fear is typically portrayed as anger, either toward the illness itself, particularly when it prevents them from participating in an activity they used to enjoy, or toward the adults in their lives, who refuse to openly talk to them about their illness. A typically laid-back and carefree child, seventeen-year-old Morris in *Swimming Upstream* (2002) becomes angry and irritable after his new diagnosis of CML. As a reflection of his fear of his sickness and the possibility of death, Morris uses this anger to distance himself from the people closest to him, like his girlfriend, who he initially avoids seeing. Through self-reflection and encouragement

⁵⁴ *Ways to Live Forever* (2010): 5:26-6:20, 30:00-31:22, and 1:03:39-1:06:31.

from a devoted sister and caring oncologist, audiences follow Morris as he matures to confront his illness and bravely fight for his health. This journey from anger to courage is part of an illness narrative that perpetuates the notion that the most admirable characters with childhood cancer are those who find the courage and resilience to lead meaningful and happy lives in the face of such a horrible illness, and such characters are abundant on screen. A common way in which their resilience is manifested, particularly for adolescent patients like Justin in *A Lion in the House* (2006), is through their use of humor, which is meant to reflect acceptance of their situation and the lack of acceptance by others who have a hard time laughing, seen in up to one-third of the films.

Love is also a frequent means through which patients are able to transcend their suffering and find such courage and resilience, depicted in up to one-fourth of the films. Kate's mother in *My Sister's Keeper* (2009) explains Kate's relationship with Taylor, a boy with AML whom Kate met in the infusion room, "The radiation, which ultimately put Kate into remission, worked its magic by wearing her down. Taylor Ambrose, a drug of an entirely different sort worked his magic by building her up."⁵⁵ While easier for another one afflicted to offer such solace because of a mutual understanding of the cancer world, in many films it is especially the love given by someone from the "normal" world that plays a meaningful role in helping a child with cancer cope with the distress caused by the cancer experience. This serves as the main narrative in the popular Hollywood film, *A Walk To Remember* (2002), a love story between Jamie, an 18-year-old girl dying from leukemia, and Landon, a popular and initially irresponsible student. When he finds out that Jamie is dying, Landon feels guilty for keeping her out too late, but she tells him, "If anything, you kept me healthy longer." He asks her if she is scared, and while she initially jokes, "To death," she tells him, "I'm scared of not being with you." The assurance he provides her when he tells her, "That will never happen. I'll be here," explains the main reason why love is

⁵⁵ *My Sister's Keeper* (2009): 43:00-45:11, 48:05-48:45, and 59:20-1:00:07.

such a potent coping mechanism for adolescents.⁵⁶ In the perfect love stories in cinema, the child with cancer is given a guaranteed companion to provide support through the arduous treatment process and to ensure that they will not be alone in death and will always be remembered. At the same time, Jamie leaves a lasting impact on Landon—“Jamie saved my life. She taught me everything about life, hope, and the long journey ahead. I’ll always miss her but our love is like the wind. I can’t see it but I can feel it.”—so that love becomes a way in which childhood cancer patients are immortalized.

Theme 7: Barren Landscape

While fictional film has to an extent reflected similar, although distorted, images of the themes related to the psychosocial stress of the cancer experience, it has begun to diverge from the experiences of the patients in *A Lion in the House* (2006) with regard to coping and support provided to address the stress. Although more focused on the patients and families themselves as well as the medical treatment team, *A Lion in the House* (2006) nevertheless portrays a wide range of characters participating in the care of pediatric patients with cancer. When Tim develops behavioral problems at school, this is addressed not only by the resident seeing him, but also by his nurse, oncologist, and an appointment shown with a mental health nurse who is a staff member dedicated to working with patients through such issues. He is given the opportunity to attend a remedial school, maintain his education, and build his self-confidence. Additionally, Tim develops a strong relationship with his nurse, Connie, which becomes pivotal to his treatment compliance and comfort with the hospital environment. He tells audiences that Connie is his favorite person, and he spends time with her and her husband outside of the hospital, depicting the truly amazing dedication of staff like nurses in the care of pediatric cancer patients.⁵⁷ *A Lion in the House* (2006) portrays a large and comprehensive treatment team, composed of oncologists, fellows, residents, nurses, a child psychologist, and palliative care and hospice

⁵⁶ *A Walk to Remember* (2002): 1:16:25-1:17:38.

⁵⁷ *A Lion in the House* (2006): Disc 2, 52:39-55:07.

specialists, who all work together to make difficult treatment decisions with a focus on the holistic psychosocial well-being of the child and family. As nicely summarized by the pediatric oncology fellow, “It’s not okay to cure a kid but leave him with residual social and behavioral issues,” this consistent focus by medical staff on the psychosocial well-being of children means that no child is emotionally abandoned by the treatment team no matter how well they are doing medically. Similarly, families are never abandoned. When Tim’s mom emotionally struggles to come to the hospital and spend time with Tim when he is dying, the comprehensive treatment team works together to meet with her, provide support and encouragement to her to find the strength to stay with Tim, and offer assistance to help contact family members and friends to strengthen her outside support network.⁵⁸ The Hollywood screen has not reflected these images of support and comprehensive care. Caricatured depictions of parental grief and coping and unrealistic depictions of children’s bravery have dominated the screen, generating a suspenseful drama around whether patients and families will sink or swim on their own in a chaotic and often unsupportive hospital environment. The physician, primarily the oncologist, remains the main hero from the medical side, who is present when treatment is an option, and who frequently abandons the family once all medical treatment options fail. In this way, fictional film presents a barren landscape in pediatric cancer psychosocial care, illustrated by the following two subthemes:

The hospital world is empty and chaotic and only there if you can be treated

Unlike the actual hospital environment depicted in *A Lion in the House* (2006), the celluloid pediatric hospitals are filled with dark rooms, long empty white corridors, and a chaotic bustle that is unaware of the patient and family who seem alone in the hospital world. In *Declaration of War* (2011), audiences are exposed to this world through the parents’ eyes. Romeo and Juliette having just learned that their son has a brain tumor and requires an operation arrive to the large hospital in Paris hoping to meet their son’s surgeon, but are instead placed in a small

⁵⁸ *A Lion in the House* (2006): Disc 2, 1:27:30-1:31:20.

room with another child and told by a nurse not to worry, “kids are not bothered by screaming from other kids.” Unable to get assurance from any staff that Dr. Sainte-Rose will be operating on their child and desiring to meet him before the operation, they stand in a hallway observing a team of doctors and attempting to guess which one will be their surgeon. Their curiosity to meet Dr. Sainte-Rose is not returned as the team scurries past them without even acknowledging their presence. Romeo and Juliette’s distress grows when they talk with the intern, who tells them that Dr. Sainte-Rose is very busy, and answers their question if he will be the one operating on their son with “Probably, I don’t know.” The following morning, the parents are suddenly awakened by a team preparing their son for surgery, quickly wheeling him down a long corridor to the operating rooms, and leaving the parents little time to say goodbye.⁵⁹ Such images of a chaotic hospital environment, minimal discussion or explanation of treatments and procedures to patients and families, and limited support from the hospital staff to accommodate families to the new hospital environment permeate the screen and are found in over one-fourth of films. Audiences are left with an increased discomfort with the structure of the hospital environment and a fear of finding themselves among such as environment.

Unlike *Declaration of War* (2011), which somewhat soothes the hospital environment with depictions of a playroom, of parents living in housing nearby, and of long and more intimate discussions between the parents and Dr. Sainte-Rose once treatment is underway, in close to 30% of the films, an aura of hopelessness is presented surrounding biomedical treatment options in the hospital environment. In *The Darkest Light* (1999), eight-year-old Matthew undergoes a lumbar puncture by a physician in an empty, dark, sterile room without any additional personnel present. It is subsequently established that chemotherapy will no longer work for him, and he does not return to the hospital even though he becomes significantly weaker and develops lower extremity paralysis. These are all just expected consequences of the cancer experience that families are expected to handle on their own. When he does finally return to the hospital to receive a bone

⁵⁹ *Declaration of War* (2011): 45:30-49:03, 50:30-52:00, and 55:02-58:48.

marrow transplant from his sister, he codes during the bone marrow infusion and no medical personnel enter the room.⁶⁰ His family stays with him while he dies, and there is no expectation of a medical or psychosocial team to help the family process and cope with the traumatic experience. In Hollywood, once childhood cancer characters are deemed incurable, they are abandoned by the hospital treatment team, and are left to deal with the dying process alone. Unlike in *The Darkest Light* (1999), in many other films this process is done at home. Given the deserted and unsupportive hospital environment, patients and families prefer it to be this way, and in one-fifth of the films, this concept of “it’s better to die at home” is emphasized. On the screen, families are the heroes of illness narratives that deal with death, and physicians take on the hero role only in narratives of successful specialized treatment with miraculous outcomes.

Psychosocial support from a treatment team is only for quitters

In illness narratives in which treatment has not been abandoned, the treatment team itself is barren, with emphasis on a single physician making all of the treatment decisions found in close to one half of films. When this physician is shown, cinema has been interested in the way in which he or she communicates with the family about diagnosis and, occasionally, prognosis. Common images are those of a hurried physician, urged by parents to provide information immediately, sharing difficult and complicated information in busy hallways with little preparation and little support after the information is given. Hollywood expects the physician to provide the medical updates and to leave the parents and patient alone to process these updates. Audiences are emotionally moved by scenes like the one in *Hello Brother* (2005), in which the parents meet in a large conference room with two surgeons who, without even introducing themselves, tell the parents, “It looks like the tumor has become quite malignant. Although we may have to give up his optic nerves, we need to remove the entire tumor to prevent relapse.” They push a consent form in front of the parents and leave the room. The parents read, “Other

⁶⁰ *The Darkest Light* (1999): 5:40-7:12 and 1:15:05-1:20:00.

risks: death, coma, blindness.”⁶¹ Hollywood physicians provide technical, specialized information, and are not responsible for the patient’s understanding of that information or of ensuring patient psychosocial wellbeing after delivering difficult news. Other staff typically responsible for such care, particularly nurses, child life specialists, psychologists, and social workers, are also absent from the Hollywood illness narratives, which thrive on families courageously surviving alone in such a technical and cold hospital environment. In over three-fourths of the films, there are limited dedicated mental health providers shown, despite the large need for these providers created by an illness narrative so concerned with the psychosocial stress of the cancer experience.

Given this large emphasis on the strength of individual families in Hollywood, it becomes almost an insult for families to be offered psychosocial support. In *Desperate Measures* (1998), the devoted oncologist, Dr. Hawkins, tells Matthew’s father, Frank, “I’m concerned about you too. I’ve learned one thing in a specialty in which we lose many patients. You have to care for the family.” Frank immediately replies, “Matt is not going to die,” and when she tells him, “We won’t give up hope, but you may want someone to talk to. The hospital has counselors,” Frank defiantly yells, “Counselors? For what? To adjust to my son dying? I don’t want to adjust to my son dying.”⁶² Psychosocial care means one has given up, and Hollywood parents rarely give up fighting for a miraculous cure or, if unattainable, for the brave acceptance of death. A similar stigma toward psychosocial care is presented in *My Sister’s Keeper* (2009) in which Kate’s psychosocial distress is viewed by her strong mother as self-pity. When Kate refuses to leave her bed because she is too sick, her mother, Sara, yells, “You’re not too sick. You’re depressed. I’m not gonna feed you antidepressants because they’re gonna just make you more numb than you already are. Now, get up.”⁶³ By addressing the psychosocial aspects of Kate’s care, Sara must confront the true reality of Kate’s terminal illness, and she is not ready to do that. When Dr.

⁶¹ *Hello Brother* (2005): 1:10:30-1:11:45.

⁶² *Desperate Measures* (1998): 13:45-14:58.

⁶³ *My Sister’s Keeper* (2009): 23:35-24:31.

Chance introduces Sara to a home health aide who talks to Sara about the Make-A-Wish foundation and whether she has considered taking Kate home, making her comfortable, and managing her pain, Sara becomes very defensive, mocking the home health aide for her “quality of life speech,” and belief in hospice care, “You think we should take Kate home to die?”⁶⁴ Sara has been devoted to fighting for Kate’s life for eight years and it is almost rude for this person she has never met before to belittle her fight by suggesting hospice care. This stigma toward psychosocial care as the last and most undesirable option in the treatment process and the absence of dedicated mental health providers on the screen, does illustrate the distress this can cause for childhood cancer patients who have a need for such care. Audiences are upset when Kate is unable to ask her oncologist about death—the amount of time she has left, whether it will hurt—because of her mother’s discomfort with engaging in such discussions and fear that they will make it a reality.⁶⁵ Therefore, while Hollywood does limit audience’s exposure to the “unsung heroes” of daily psychosocial care for pediatric cancer patients and their families, and illustrates the stigma associated with such care, it does leave audiences questioning whether avoiding such care is appropriate. Unfortunately, in most cases, the heroic and resilient childhood cancer character and family is left unscarred by the lack of psychosocial care so that audiences are not convinced of its need and are left unaware and devoid of images of the benefit it can provide.

⁶⁴ *My Sister’s Keeper* (2009): 40:22-41:56.

⁶⁵ *My Sister’s Keeper* (2009): 38:50-40:21.

V. DISCUSSION

This study presents an original analysis of the childhood cancer experience as depicted in contemporary film. Over the last two decades, the appearance of childhood cancer on the screen has multiplied, and childhood cancer illness narratives have been found across all film genres and in films produced in countries throughout the world. Through these illness narratives, an image has emerged of the celluloid childhood cancer patient and his/her illness experience that has the potential to drive public discourse about pediatric cancer care given the little exposure the public otherwise has to pediatric patients with cancer.

A. The Cinematic Childhood Cancer Narrative: Is the Celluloid Mirror Accurate?

In the biomedical realm, this study shows that the celluloid image has been an unrealistic one of bleak outcomes similar to the findings by Lam et al. 2011 (55). While the epidemiology of childhood cancers on the screen appropriately shows leukemia and CNS/brain tumors as the most common pediatric cancers, highly aggressive and unresponsive variants permeate the screen. Commonly, the pediatric character suffers from a cancer that has not responded or is unable to be treated by available therapies. Relapse rates are high, over 25% in cinema versus less than 10% in current practice. Similarly, a treatment option typically reserved for the most severe cases, bone marrow transplantation is commonly presented by cinema, undertaken for 31% of childhood cancer characters versus 1-2% of real pediatric patients with cancer (16). On the screen, this study shows that childhood cancer is still a largely incurable disease, with a mortality rate of 66%, similar to the findings by Lam et al. 2011, who showed a 75% mortality rate for cancer in children and young adults in film (55). This cinematic mortality rate is significantly higher than the actual mortality rate of 16% for all childhood cancers shown by current statistics (16). These bleak cinematic outcomes reflect a society that continues to fear cancer, a mysterious disease whose cause is unclear and whose treatment and course is unpredictable.

The large advancements made in pediatric cancer treatment and outcomes over the last six decades have not been reflected in film, a medium in which childhood cancer outcomes have remained unchanged over the last two decades, reflecting clinical outcomes seen in reality in the mid-twentieth century. Film seeks to foster deep emotional reactions from audiences, and thus has continued to garner societal pity for children with cancer by perpetuating the notion that a child with cancer will most likely die. In film, which must beautify the pediatric cancer experience to make it appropriate for viewing by a broad audience, bleak outcomes are used to depict the suffering inherent in pediatric cancer. As this study has shown, film has created a publicly available image of pediatric cancer as a tragic bald and weak child who will most likely succumb to the disease. Fortunately, the child will do so through a process in which his/her functionality and childhood vitality remain strongly present until the moment of death, a cinematic depiction that is starkly contrasted by the intimate images of real patients in *A Lion in the House* (2006). Rather than improvements in outcomes, it is this caricatured resilience of children and families in the context of an awful disease that has been used by film to provide audiences hope for the quality of life of pediatric patients with cancer.

Unlike the limited change seen in the presentation of outcomes in childhood cancer on the screen in the last six decades, in the psychosocial realm, an area on which pediatric oncology has increasingly focused, film has made large strides in depicting the myriad psychosocial stressors faced by pediatric patients with cancer and their families. As shown in the coding structure of psychosocial stress and in the thematic analysis, unlike earlier cinematic pediatric cancer illness narratives, which largely focused on conflict outside of the realm of the pediatric patient him/herself, current narratives largely concern themselves with the personal and social context of the illness experience for the patient and family. Concepts only briefly exposed in the small number of films with a character with childhood cancer released prior to 1990, the new cinematic childhood cancer narrative willingly exposes audiences to the lifestyle disruption, social isolation, psychological and emotional distress, and physical distress of the pediatric cancer

experience. Similarly, an increased awareness of the ethical dilemmas surrounding end-of-life care, treatment decision-making, and childhood patient autonomy exists on the screen, and its complexity has been increasingly explored over the last two decades. Although, as described in the thematic analysis, some of these celluloid images of psychosocial stress can be exaggerated and simplified to satisfy the Hollywood narrative, they fairly accurately reflect stressors faced by real patients and families—as was found in a study that used group discussions and individual interviews of children with cancer, their parents, and hospital professionals to identify the major stressors and their physiological and psychological effects experienced by children diagnosed with cancer and their families (75).

Despite cinema's success at reflecting the psychosocial stressors associated with the pediatric cancer experience, a distorted image emerges when it comes to reflecting the coping and psychosocial care provided to address these stressors. Pediatric patients with cancer and their families in film, as shown by the quantitative analysis of psychosocial support and in the thematic review, are left alone to handle the psychosocial stressors that they encounter. As thus expected, overall psychosocial support provided to characters with childhood cancer on the screen is generally poor. Parents and close family and friends who are shown to be the main providers of support in film are not provided with the necessary guidance to adequately address the sick child's unique psychosocial needs. Parental grief and subsequent avoidance of addressing the cancer experience with the child or obsession with fighting for every last treatment option are frequent cinematic images that typically cause the child to feel neglected and experience increased worry and distress. The child further receives limited support from medical professionals who, in film, are typically a single oncologist who presents biomedical information to the family only when treatment is still an option. Dedicated psychosocial support staff, which have been reported to be available in 80% of Children's Oncology Group institutions, are rarely reflected by the celluloid mirror (23). When they are mentioned or shown, it is typically in highly stressful medical scenes, such as in end-of-life discussions as described for *My Sister's Keeper*

(2009) so that they become equated with a euphemism for medical providers to suggest that parents give up and accept a child's death.

On the screen, psychopathology is a sign of self-pity and weakness, and addressing it would only acknowledge these unwanted traits. As celluloid childhood cancer characters must be the heroic, resilient, and mature patients that please and inspire audiences, there is little room for psychosocial care on the screen. In this way, cinema creates an expectation that childhood cancer patients and families should and are capable of confronting the psychosocial stressors associated with the pediatric cancer experience with courage and poise, and while they are allowed to falter and experience moments of weakness along the way, in the end they almost consistently victoriously accept, find meaning, and grow through the arduous experience. Offering support and help along the way would only limit this development and growth for the child and family. Therefore, the celluloid mirror has reflected a barren and empty psychosocial care structure that is very different from the expected current practices as developed by the SIOP Working Committee on the Psychosocial Issues in Pediatric Oncology (63-73), **Table 10**). This is particularly concerning in the context of a cinematic medical scene that so frequently deals with particularly difficult cases, treatment modalities, and outcomes. Like the lack of improvement in pediatric cancer outcomes on the screen, there have been no discernible changes in the depiction of psychosocial support provision in film over the last six decades despite the large improvements in pediatric psycho-oncology that have occurred over that time. Such a cinematic image of limited dedicated psychosocial care perpetuates the public stigma associated with being an individual who needs psychological help that has been suggested as a barrier to the optimal provision of psychosocial care in oncology (19, 24).

Table 10. Pertinent SIOP Working Committee Guidelines and their Presentation in Fictional Film

Psychosocial Issue	Guidelines Presented by the SIOP Working Committee	Depiction of the Same Concept in Film
School/Education (72)	School in the hospital (in-hospital teachers; play therapy; multi-disciplinary team) School re-entry program (discussion with and manual for school teachers; discussion of illness with child's classroom; support to keep up with school at home) Personalized education program	Except 1 institutional setting, no school experience in the hospital One teacher addressed child's illness with classmates, otherwise child left alone to re-integrate, most abandon education Home tutor for one child
Diagnosis Discussion (64)	Private, comfortable space Oncologist, PCP, head nurse, other staff, child, close family or friends can participate Pertinent psychosocial suggestions made at first meeting; Linked to support groups Direct, separate discussion by trained staff with child based on child's age and development level Encourage parents to talk with child Staff conducts informational sessions with extended family, child's peer group, teachers Elicit questions/concerns from child and parent	Often in crowded hallways One oncologist and one or both parents Psychosocial care never initiated at diagnosis Parents give diagnosis to child, occasionally oncologist talks to adolescent patient Parents struggle alone to do this Families left alone to inform family and friends Child/parent expected to passively accept the information provided
Assistance to Terminally Ill Child (66, 73)	Decision to transition to palliative care made with parents, health-care team, and child Medical decisions made by comprehensive	Decision process rarely shown, and typically made by one provider

Table 10. Pertinent SIOP Working Committee Guidelines and their Presentation in Fictional Film

Psychosocial Issue	Guidelines Presented by the SIOP Working Committee	Depiction of the Same Concept in Film
	<p>“caring” team, not one physician acting alone</p> <p>Children who wish to stay at home should be allowed (continued psychological and physical symptom management should be provided)</p> <p>Child should never feel abandoned (follow-up visits and telephone calls by treatment team)</p> <p>Bereavement counseling for providers and parents/family after child’s death</p>	<p>One physician makes decisions</p> <p>Children are allowed to die at home, but limited care provided by treatment team at end-of-life</p> <p>Children typically abandoned by treatment team if cure not possible</p> <p>No counseling or support shown after child’s passing</p>
Assistance to Siblings (67)	<p>Medical team speaks to parents about need to support siblings; gives guidance how to do so</p> <p>Team discusses with siblings in age-dependent manner the expected changes and emotions</p> <p>Share with parents the need to keep siblings informed from the beginning and throughout</p> <p>Establish psychosocial support program for families (ex. sibling support groups)</p> <p>Siblings should enter decision-making process about whether they wish to be BMT donors</p> <p>Siblings should be brought into the discussion about palliative care and death itself</p> <p>Available resources for bereavement and mourning should be provided</p>	<p>Parents not encouraged or guided about sibling support</p> <p>Siblings not prepared for anticipated changes and emotions</p> <p>Siblings rarely informed and are distressed by this</p> <p>Families not incorporated into psychosocial support program</p> <p>Siblings are engaged in discussions about BMT donation</p> <p>Sibling discusses death brother/sister, rarely parents</p> <p>No resources for mourning or coping after death provided</p>

Table 10. Pertinent SIOP Working Committee Guidelines and their Presentation in Fictional Film

Psychosocial Issue	Guidelines Presented by the SIOP Working Committee	Depiction of the Same Concept in Film
Treatment Discussion and Compliance (69, 71)	<p>Open, honest, thorough communication with patients/families; PCP included in discussion</p> <p>Psychosocial members of the health care team play crucial role in adaptation to treatment side effects</p> <p>Health care team can help families find place near the hospital to stay and find resources to help families with other aspects of their lives (finances, sibling care, etc.)</p> <p>Remain non-patronizing and open to discussion when alternative treatments are proposed by families</p> <p>Assure parents and patients that no matter what happens, the medical staff will take care of the child until the end</p>	<p>Treatment abruptly presented with limited discussion about them</p> <p>Children and families left alone to cope with side effects which are often distressing to the children</p> <p>Family expected to find resources and adapt to life with a child with cancer on their own</p> <p>In 1 film that discusses alternative treatments, oncologist is open-minded and involved</p> <p>Child and family frequently abandoned by medical team at the end-of-life once treatment fails</p>

B. The Celluloid Experience in the Meta-Narrative of Childhood Cancer

In the evaluation of the celluloid ECT experience described in the introduction, the authors concluded that “Characters and events in films pay less heed to factual accuracy than to the demands of film narrative, which restricts the depiction of complex solutions for complex problems” (29). A similar conclusion is drawn by this study of the celluloid pediatric cancer narrative. It is no surprise that film, whose purpose is to entertain a large and intellectually diverse audience, has focused on the fundamental, most thrilling and suspenseful concept in the

childhood cancer experience—the opposition between life and the threat of death. In this context, with a focus on the physical and psychological demands of confronting such an opposition, the film industry has been able to present the complex problem of pediatric cancer. Furthermore, it has been able to do so with increasing complexity and depth over the past six decades as cancer has become less taboo. However, with regard to solutions, film falls short, unable to portray the complexity of caring for a pediatric cancer patient in a biopsychosocial framework. Therefore, the most entertaining aspects of care—dramatic medical treatments and procedures with a focus on the oncologist, the medical professional who is most directly involved in answering the question of life or death for the patient—are emphasized on the screen. Outside of this realm of care, families are abandoned to cope with the psychosocial effects of the treatment process on their own, a convenient tool for the film narrative to convey character identity and development. Therefore, to conserve the entertainment value of the pediatric cancer narrative, cinema has failed to reflect the advancements in outcomes and psychosocial care in pediatric cancer, areas that have remained unchanged on the screen in the last six decades, but have undergone tremendous changes in clinical reality. The problem is that audiences, who have limited exposure to the care of pediatric patients with cancer, might not be able to make the distinction between the needs of the film narrative and medical accuracy (76). Audiences may thus come to associate the pediatric cancer experience with that of courageous and resilient children and families who battle the cancer experience alone, helped by a heroic oncologist when treatment is available, otherwise expected to bear the burden of the disease alone. They are left unaware of the multidisciplinary team of providers who are typically involved in the care of pediatric patients with cancer, with a limited expectation for psychosocial support by the medical treatment team and dedicated support staff, and with the persistent stigma that psychosocial support is for the “weak” and is to be avoided.

While it is difficult to prove this effect of the childhood cancer narrative depicted in film on audiences, this analysis serves to present yet another story in the meta-narrative of pediatric

cancer in media, which taken as a whole has been consistently shown to affect the behaviors and attitudes of the public at large. The image and discourse surrounding childhood cancer in cinema adds another example to the general notion that “media stories of childhood illness and disability typically involve inspirational narratives of children heroically overcoming obstacles” (53).

Similar to the studies of written text introduced earlier, the celluloid pediatric cancer narrative portrays cancer as an intruder in the child’s life that disrupts normal childhood experiences and threatens the rights of children to their child-like activities, innocence, and ability to dream for the future. Childhood cancer patients, like in written text, are idealized by cinema for their bravery, ability to endure suffering, and ability to inspire those around them. In both media sources, hair loss is emphasized with regard to the physical effects of cancer and is associated with the tragedy of the cancer experience. The effects of childhood cancer on parents, such as financial burden, loss of employment, the obligation of proximity, sacrifice, grief, and emotional distress are also highlighted by both media types. The “struggle” discourse surrounding pediatric cancer in written text is accentuated by a combination of dialogue and images of struggle on the screen, often presented through a war metaphor. While written accounts emphasize parents as fighters, cinema addresses parents’ psychosocial needs and psychological conflict and coping. In both, however, an image of parents as self-sacrificing and optimistic eventually emerges. Finally, like written text, cinema leaves out life after cancer and instead emphasizes “the moment of triumph or despair when either child or disease is the victor” (53). In both, there is a substantial lack of how children’s and parents’ psychosocial needs are addressed by the healthcare system. As this analysis of pediatric cancer in cinema is the first analysis of the pediatric cancer illness narrative outside of written text, it substantially contributes to and strengthens the meta-narrative that is being developed about childhood cancer as constructed by the media.

C. Using Cinema-Education to Teach Oncology Providers about Psychosocial Care

As described in the introduction, optimizing psychosocial care in pediatric oncology requires both a more standardized implementation of scientifically proven interventions early on in the cancer treatment process across all institutions as well as increased training for pediatric oncology providers in the field of psycho-oncology (22, 24). Film has been shown to be a useful medium for teaching concepts involving the personal and social context of illness because of its unique ability to captivate audiences in an illness narrative (46-48, 50, 77). Through this analysis of films involving a childhood character with a cancer diagnosis, five films have been identified as particularly useful for teaching concepts in pediatric psycho-oncology that have also been highlighted as important by the SIOP Working Committee guidelines (63-73). Of note, *A Lion in the House* (2006) was included in this analysis but is not presented here because there already exists a detailed educational curriculum utilizing scenes from this documentary (78). **Table 11** presents the five films and the concepts that can be addressed by viewing of these films. Providers can supplement the overall cinema analysis presented in this study by viewing these five films to develop a personal understanding of the pediatric cancer narrative in cinema. Discussion among providers and individuals directly involved in providing psychosocial care, such as social workers, can then occur to reflect on and utilize these cinematic images to encourage ideas about the optimal provision of psychosocial care. Additionally, the DVD provided at the beginning of this book contains particularly useful scenes from these five and additional films organized by the themes and can also be used in the teaching of pediatric psycho-oncology via the associated concepts for discussion. Providers are encouraged to address these images with patients to fully understand their patients' expectations for biomedical and psychosocial care, and as an avenue to address the importance of initiating psychosocial care early in the treatment course.

Table 11. Films of Interest for Teaching Pediatric Psycho-Oncology

Film	Concepts for Discussion
<i>Ways to Live</i>	Integration of school/education during treatment
<i>Forever</i> (2010)	Communicating with the dying child (providers and parents) Support for the child who chooses to remain home for palliative care
<i>Declaration of War</i> (2011)	Communication of the diagnosis Social support and resource provision for parents Supporting parent adaptation to the new hospital environment
<i>Oscar and the Lady in Pink</i> (2009)	Communicating with the dying child (providers and parents) Support for the child in the hospital receiving palliative care Support and bereavement counseling for family and friends when a child dies
<i>My Sister's Keeper</i> (2009)	Child involvement in medical decision-making and discussion about palliative care Sibling support, involvement in care, and potential neglect Sibling decision-making about donation
<i>Hello Brother</i> (2005)	Communication of the diagnosis Sibling support, involvement in care, and potential neglect Communication about treatments and procedures with the child and parents

D. Ethical Considerations

While it is not possible to delve fully into the ethics involved in portraying illness narratives through audiovisual means, the inclusion of the documentary *A Lion in the House* (2006) as part of this study raised several ethical questions while viewing particularly intimate scenes of suffering and end-of-life coping in the documentary. While the families all agreed to the filming of these intimate scenes and were repeatedly made aware of their rights to refuse taping at a particular time or to fully remove themselves from the documentary altogether, it is unclear how these rights extended to the children themselves. Were they capable of understanding that their dying bodies would be portrayed on the screen and viewed by mass audiences, and could they—

given their ages and state of health—adequately consent to having such images shown? In an interview by the Independent Lens, one of the film directors, Steven Bognar, states:

We were not about to stop filming these families who lost their kids, just because they lost their kids. If the families told us to get lost, then that's one thing. But if they were willing to let the cameras be there, then they had to be there. We had been through something with them. We had been through something horrible and traumatic with them and we had to stick with that (79).

An interesting distinction between confidentiality and privacy is brought about by this documentary technique of cinema verité or observational filming (80). When the content of film is not fiction but people's lives, filmmakers are placed in an emotionally sensitive position. They are expected to act as a "fly on the wall," and regardless of "how uncomfortable a situation gets or how much [they'd] like to leave, [they] have to steel [themselves] to stay. [They] have to steel [themselves] to be 'intrusive' (80). However, the question remains whether the intrusion into a very personal matter (such as a child's death) should be broadcast, or if there are some private experiences that should remain confidential regardless of whether the subjects who were filmed had given their consent. This highlights the tension between academic narrative and the risk of media dramatization which can distort these narratives (81). Although this question of whether there should be moral—based on fundamental ethical principles of privacy—censorship of reality remains debated, it is fairly evident that there will be increasing ethical challenges to the production of films like *A Lion in the House* (2006). Fictional films, however, allow such private moments to be depicted without threatening individual privacy or confidentiality, and avoid general moral apprehension about mass audiences bearing witness to real and intimate suffering that can be abused for a dramatic and entertaining effect. Interestingly, it is especially these private moments, such as difficult and invasive procedures or the process of dying, that are avoided by fictional films, which could serve to educate and generate discussions about such topics. It remains to be resolved whether such topics are appropriate for mass viewing either through the fictional or documentary genres.

E. Limitations and Future Research

There are several limitations to this analysis of pediatric cancer in cinema. The evaluation of all of the variables described was primarily done by a single investigator, which may have created a subjective bias to data generation. While a standardized structure was created in an attempt to minimize this, its reliability must be confirmed by review of all of the films using the algorithms developed by additional investigators. Nevertheless, thematic content was developed through multi-investigator discussions and collaboration, and involved investigators with different backgrounds in pediatric cancer. Furthermore, techniques in quantitative media health content analysis and qualitative research methodology were used and based off of prior media health content research to strengthen their validity. Also, as this is the first study of pediatric cancer in cinema to date, the methods presented provide a solid foundation for future research efforts, which can confirm their reliability and strengthen their validity. At this time, however, the study is limited by novel methodology for describing the highly complex concepts of pediatric cancer and psychosocial care, which must be confirmed. A final limitation of this study is its primarily descriptive nature. While inferences were made by the investigators as to the meaning of the study results for the public perception of pediatric cancer care, such a link is unable to be proven. It is difficult to quantify the exposure of the public to the content presented in these films, and although the most easily available and contemporary films were selected, it has not been shown that the public utilizes such images in forming their knowledge of pediatric cancer care. The similarity of the results of this study to the results of studies evaluating pediatric cancer narratives in other media, however, suggests that a meta-narrative of pediatric cancer in media exists, and this study contributes to the development of that meta-narrative.

Within the available content and data presented in this study, additional research can, in more detail, analyze specific components of pediatric cancer care to maximize what can be learned from studying cinematic images. For example, by focusing specifically on the discourse and images presented with regard to communication of the pediatric cancer diagnosis on the

screen, ideas can be developed about how audiences expect health care professionals to communicate and interact with patients and more specific educational goals can be established to teach medical providers appropriate communication skills through film. Other such areas that can be studied in more detail through cinema include care of siblings of pediatric cancer patients, communication with pediatric cancer patients about death, and cancer discourse among young children. Subsequently, more specific and detailed educational curricula can be developed for pediatric oncology providers that utilizes film to teach concepts of psychosocial care. Research will be needed to validate the usefulness of such an educational program. Analysis is also needed to evaluate how these film depictions of pediatric cancer affect public knowledge and attitudes regarding cancer care. Studies similar to the one evaluating medical student perceptions of ECT treatment before and after viewing film clips of ECT administration are needed to evaluate the direct effects of the celluloid pediatric cancer narrative on public perceptions of the illness, including both those with direct experience with pediatric oncology patients and those with no such experience (45).

In this study, the documentary film *A Lion in the House* (2006) clearly stands out from the fictional films, and was included as it provided a unique backdrop for exploring the images portrayed in fictional film and promoted many discussions and ideas that were fundamental to the project design and evaluation of the fictional films. However, as its own separate genre, documentary films portraying childhood cancer should be evaluated in a similar manner to this study in order to understand how pediatric cancer has been portrayed by this type of media. This will not only further contribute to the meta-narrative of pediatric cancer in media, but will also allow more direct and complex comparisons to be made between the audiovisual images of pediatric cancer presented in documentary versus fictional film which will enhance the educational potential of both genres. This study, as well as these future potential studies, can all serve to create a foundation through which medical providers or social workers can collaborate with filmmakers and Hollywood, via organizations like the USC Annenberg School for

Communication and Journalism Hollywood, Health, and Society Program⁶⁶, in the creation of future cinematic images of pediatric cancer (82).

F. Conclusion

This study presents an original analysis of pediatric cancer in 29 commercially and readily available feature-length films, utilizing quantitative and qualitative content analysis to describe the celluloid childhood cancer experience. Quantitative evaluation of medical care of pediatric cancer characters in film confirmed the hypothesis that cinema paints an unrealistic, bleak picture of childhood cancer with a predominance of untreatable cases and poor outcomes. A more focused mixed approach was applied to evaluate the complex phenomena of psychosocial care. This showed that the celluloid childhood cancer narrative reflects a range of psychosocial stressors that are consistent with those experienced by actual patients and families, but a barren landscape with regard to psychosocial support and care. As hypothesized, psychosocial support in cinema is focused on resources already available to families prior to their diagnosis rather than professional dedicated psychosocial supports. These quantitative and qualitative descriptions were further expanded by a thematic analysis of disruption, social impact, psychological impact, physical toll, struggle/war/fight, coping, and the barren landscape in the celluloid childhood cancer narrative. This analysis confirmed that the childhood cancer narrative in cinema contributes to the growing meta-narrative of childhood cancer in media that empathizes images of an isolated family courageously battling the psychosocial stressors associated with caring for a pediatric patient with cancer with limited support from a treatment team solely dedicated to medical care. The absence of psychosocial care in media is in contrast to the growing presence and involvement of psychosocial care teams in pediatric cancer. The generally ignorant and

⁶⁶ Hollywood, Health & Society: A Program at the USC Annenberg Normal Lear Center that provides entertainment industry professionals with accurate and timely information for health storylines. In partnership with funding agencies, which includes the National Cancer Institute, they offer resources, including quick facts, briefings and consultations with experts, case examples, panel discussions about timely health issues, and an expanding list of tip sheets, written specifically for writers and producers (82, 83).

negative view toward psychosocial care in cinema can play a role in perpetuating the stigma that still exists around psychosocial interventions and that serves as a barrier to optimizing psychosocial care provision. This analysis and pertinent scenes from these films can thus be used to educate pediatric oncology providers about important concepts in pediatric psycho-oncology, and promote discussion between providers and patients about potential pre-conceptions about psychosocial care early in the treatment process to ensure that such care is not abandoned in actual practice as it is, for entertainment purposes, on the screen.

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Were they discussed with patient/family?

Patient/family perspectives regarding the psychopathology:

Specific psychiatric/psychological treatment (psychotherapy/counseling, psychotropic medication):

Psychosocial Stress:

Patient:

Parents:

Sibling:

Family:

Financial:

School:

Living Situation:

Social:

Sources of Psychosocial Support:

Internal, Non-Professional Psychosocial Supports (Nuclear and close family):

External Non-Professional Psychosocial Supports (Significant others, friends, clergy, coaches, teachers, etc.):

Professional Medical Supports (Oncologists, nurses, specialists):

Professional Psychosocial Supports (Social work, child life, psychologist, psychiatrist, mental health nurse, chaplain/clergy in hospital, palliative care professional):

Stigma:

About Cancer:

About psychiatric/psychosocial aspects:

About treatment team:

Ethical Dilemmas:

Specific Themes Identified:

General Notes:

Primary Notes While Watching Movie:

B. Film Analysis Document – *My Sister’s Keeper* (2009) Example

Film Analysis – *My Sister’s Keeper*

Note: Indicate times (start, finish) of clips that highlight any of the relevant themes below

General Movie Description:

Title: My Sister’s Keeper **Year:** 2009 **Genre:** Drama

Director: Nick Cassavetes

Producers: Stephen Furst, Scott Goldman, Mark Kaufman, Diana Pokorny, Mendel Tropper

Company: Curmudgeon Films, Gran Via Productions, and Mark Johnson Productions

Country: USA **Language/Subtitles:** English/English and Spanish

Release and Sales Information: Released June 26, 2009, gross domestic earnings \$49,185,998 as of Oct 4, 2009.

Noteworthy Prizes/Awards: 2010 Young Artist Awards winner of the Young Artist Award for Best Performance in a Feature Film – Leading Young Actress for Abigail Breslin and Best Performance in a Feature Film – Supporting Young Actress for Sofia Vassilieva, 2009 Teen Choice Awards winner of Teen Choice Award for Choice Summer Movie: Drama.

General Synopsis: In Los Angeles, the eleven year old Anna Fitzgerald seeks the successful lawyer Campbell Alexander trying to hire him to earn medical emancipation from her mother Sara that wants Anna to donate her kidney to her sister. She tells the lawyer the story of her family after the discovery that her older sister Kate has had leukemia; how she was conceived by in vitro fertilization to become a donor; and the medical procedures she has been submitted since she was five years old to donate to her sister. Campbell accepts to work pro bono and the obsessed Sara decides to go to court to force Anna to help her sister.

Main Characters (Name of characters and actors):

Kate Fitzgerald (patient) – Sofia Vassilieva; Sara Fitzgerald (mom) – Cameron Diaz; Anna Fitzgerald (sister) – Abigail Breslin; Brian Fitzgerald (dad) – Jason Patric; Jesse Fitzgerald (brother) – Evan Ellingson Aunt Kelly – Heather Wahlquist; Campbell Alexander (lawyer) – Alec Baldwin; Judge De Salvo – Joan Cusack; Taylor Ambrose (boyfriend) – Thomas Dekker; Nurse Adele – Lin Shaye; Nurse Susan – E.G. Daily; Dr. Farquod (oncologist) – Emily Deschanel; Dr. Chance – Jeffrey Markle

Plot Keywords: Leukemia, terminal illness, oncology, cancer, sick child, death of child

Medical Aspects:

Patient: Kate Fitzgerald **Age:** 15 **Gender:** Female

Cancer Diagnosis: Acute Promyelocytic Leukemia

Comorbid Medical Illness: Renal failure

Treatment (Chemo, radiotherapy, surgery, stem cell transplant, novel or experimental treatments): Chemotherapy, radiation, cord blood transplant, bone marrow transplant, white-cell infusion, dialysis

Side-Effects Experienced (from treatment and cancer): From cancer, bleeding (epistaxis, bruising, hemoptysis), fatigue, difficulty walking (in wheelchair at end). From treatment, hair loss, immunosuppression (fever, coughing, sepsis), nausea/vomiting.

Complications: Relapse, organ failure

Outcome: Death

Discussion of diagnosis including initial reactions:

9:45-10:18 (Mom takes Kate to doctor long time ago because she's always tired and see a big bruise on her back): Doctor's room with lots of toys; doctor sits with mom in her office later and tells her, "Kate's white cell count is much lower than normal... She may have an autoimmune deficiency. Could just be a lab error." Gives her card for oncologist, and mom says, "Oncology? But that's cancer."

10:25-10:51 (Parents meet with oncologist, Dr. Farquad): She sits down next to them in the waiting room and immediately starts telling them, "So I took a look at Kate's CBC. Her white blood count is very low. She's also presenting with 12% promyelocytes and 5% blasts which does indicate a leukemic syndrome." (Parents ask "Leukemic?") Dr. Farquad tells them, "Cancer. I'll need a bone marrow aspiration to confirm but it seems that Kate could have what is called acute promyelocytic leukemia. I'm sorry." (Parents immediately start crying, news given very suddenly without ascertaining parent's knowledge, worries, desires for how much information to receive, etc.)

Parents discuss diagnosis after: Dad says "St. Joe's doesn't know shit. You remember when the chief's son was playing with Jesse and broke his left arm? They put a cast on his right," and wife tells him, "I'm not gonna let her die. You know that, right? I'm not." (father in denial, hopeful it's a misdiagnosis, mom defiant and ready to fight the cancer)

Discussion of prognosis including reactions to prognosis and possible death:

13:20-14:00 (doctors come to tell family news about prognosis): two doctors come and sit in circle with whole family in Kate's room. "Kate's leukemia is back. She's no longer in remission. We've looked at her smear, and her leukemic cells are showing at 23%. (How many is bad?) Any. (What about chemo?) It's an option, but Kate doesn't seem to take it very well. And her cancer may be too far along. (So you need more bone marrow?) Yes, but the leukemia isn't Kate's biggest problem now. She's lost the function of her kidneys. They've quit. They're gone." (Doctors are compassionate, give an honest prognosis, sit down with family, take time to explain situation).

38:50-40:21 (mom and aunt in Kate's hospital room, chatting and laughing): Doctor comes in and asks her the pain level and she tells him 6 and he says all right, let's take care of that. He then talks to mom in the corner of the room in hushed voices and when mom says "She's feeling pretty good today," he tells her, "Sara, these lucid moments are gonna get briefer and further apart. Kate's in system failure now. Body defenses are at zero. The fevers Kate's been getting, it's infection from the dialysis. And it's not just in her arm or leg, it's in her blood. I'm sorry, Sara, this is it. We're at the end." Kate is looking on, looks sad, and calls to Dr. Chance, he tells her, "What is it, princess?" and walks over and sits by her, she says, "No good, huh?" He tells her no and when she asks how long, he says, "It's hard to say. But if nothing changes, not too long." Kate's eyes fill with tears, mom immediately comes in and says, "Not too long? Not too long what?" Kate continues asking questions, "Will it hurt?" and doctor tells her, "No. I'll make sure of that." Mom again jumps in and says strictly, "Listen, I don't wanna hear talk like that, okay, honey? You just stay strong enough for surgery, okay?" Kate says, "Okay, Mom," to please her as her aunt holds her hand and kisses her. (Dr. Chance very compassionate, sits close to Kate, shows respect for her wishes and her desire to know, balancing mom's and Kate's wishes)

25:34-26:26: Kate knows she is going to die and is okay with it

Discussion of treatments:

10:51-11:15: Kate gets bone marrow aspiration as mom watches through the window; no one has explained anything to Kate yet about diagnosis or why she needs the procedure. (young Kate)

Psychopathology:

Diagnoses: Depression (suicidal attempt – Kate gets drunk alone in room, overdoses on pills)

Were they discussed with patient/family? No

Patient/family perspectives regarding the psychopathology: Not real psychopathology, just form of self-pity, she should be able to snap out of it and overcome it on her own.

Specific psychiatric/psychological treatment: None

Psychosocial Stress:**Patient:****Effects of disease on those around her:**

25:38-28:54 (Kate talking as she looks through her scrapbook): “This is it. I know I'm going to die now. I suppose I've always known that. I just never knew when. And I'm okay with it. Really. I don't mind my disease killing me. But it's killing my family too. While everyone was so worried about my blood counts, they barely even noticed that Jesse was dyslexic. (go to a scene in the past where parents sitting with Jesse telling him about camp with special teachers for him, he tells them he'll try harder, parents explain to him that things are just mixed up in his head and the camp will help, he cries and agrees to it) I'm sorry, Jesse. I'm sorry I took all the attention when you were the one who needed it the most. Dad, I know I took your first love from you. I only hope that one day, you get her back. Mom, you gave up everything for me. Your work, your marriage, your entire life just to fight my battles for me every single day. I'm sorry you couldn't win. And to my baby sis, who was always so very little, I'm sorry I let them hurt you. I'm sorry I didn't take care of you. It was supposed to be the other way around.”

Embarrassment/anger at being sick, lack of normalcy in life, pain/physical changes → decreased self-esteem:

5:42-6:15 (Kate gets sick with fever): Anna goes to find Kate and sees her in bathroom with bloody nose, coughing, looks embarrassed and angry.

See her go dress shopping with all the girls in her family, and she gets angry because she doesn't look good, and wants to cover up her head, she ends up buying a wig and looks beautiful for the dance (whole family so excited, taking pictures of her, looks like normal family getting ready for prom)

Multiple times in film, Kate shown telling family that she is ugly because she is bald, mom even shaves her own head to help Kate deal with the physical changes.

1:20:42-1:21:24: Kate gets drunk and overdoses on pills in her own room

Parents:

Anna talks about her family: “Since my sister got sick, things have changed, my aunt works part time and my mom quit her job as a lawyer...her life now revolves around keeping Kate alive, cooking and cleaning.” she tells us everything has to be organic, clean, and germ free (mother has become obsessed about caring for Kate and devotes all her time to it)

5:10-5:35 (Dad's voice): “Having a child who is sick is a full-time occupation. Sure, we still enjoy the usual day-to-day happiness of family life—big house, great kids, beautiful wife—but beneath the exterior,

there are cracks, resentments, alliances that threaten the very foundation of our lives...as if at any moment our whole world could come tumbling down.”

Doing everything possible to help child, keeping up to date with all medical information, never giving up fight:

12:30-13:00 (Katie gets very sick and doesn't want to open door to let anyone help her, mom had to kick door down; Siblings run in to see and they look terrified as does Kate herself as EMT puts her on stretcher): During scene, there's a lot of blood, mom tells them that they need to get platelets and fluid into her because she doesn't want her going into shock. Mom tells them she's 15, about 90 pounds, she's allergic to penicillin (mom seems to know the medical information well and has prepared herself to handle these horrifying moments)

When Aunt tries to mother that she has to see the bigger picture and that you can't just keep fighting all the time and need to stop, mom tells her, “I can't.”

Parental discord about goals of care and what is best for child causing strain in parent's relationship, also stress about taking care of other kids while also wanting them to help Kate:

1:08:36-1:09:34: Dad picks up other kids from school and gets everyone together to take her to the beach, mom freaks out about it and yells at dad, “I don't give a shit who you talked to! You are killing her! You understand? Take her to the beach, you kill her!” Kate starts crying, mom tells him, “See how upset she is? See what you're doing? I'll call cops. He tells her, “Do what you gotta do. - Last 14 years I've let you have it your way. Last 14 years have been about saving her!”

Today is not about you. It's about Kate. She wants to go to the beach.” Mom keeps yelling that she will die and dad says if she doesn't come he'll get a divorce. (mom eventually joins them at the beach)

**In general, mom is portrayed as the fighter who has lost her grip on reality while dad is depicted as more thoughtful, patient, understanding and insightful about the futility of treatment for Kate and respecting Anna's wishes (Dad tells mom to take a breath at the dinner table, not sure he wants to make a donor baby, listens to Anna and takes her to firestation after mom gets mad at her, discusses respecting Anna's wishes rather than forcing her with mom at firestation, takes Kate out of hospital for a day at the beach)

Accepting that the child will die (whole family must deal with this stress and they all come to cope with this at different stages and times which creates a lot of discord among the family members at a time when they all need to come together for each other:

1:20:24-1:24:00 (Anna called to witness stand): Mom questions her, “You love your sister, right? You know she's sick. Why won't you help her?” (go to scene of Anna finding Kate drunk in her room having a going-away party by herself, breaking everything in her room, taking pills, and Kate yells no) Jesse interrupts during the trial and questions Anna if medical emancipation is really all that they're here about. Mom tells Anna that it doesn't add up and that she's hiding something, “People give their kidneys to total strangers. You'd better start talking right now. You're not telling the truth, because if you are, I don't know you.” Jesse starts yelling for Anna to tell the truth, and finally Jesse yells out, “God, you people are so stupid! Kate wants to die! She's making Anna do all this because she knows she's not gonna survive. (Mom - That's a lie, Jesse!” Oh, no, it's not! Kate's dying and everybody knows it. You just love her so much that you don't want to let her go. But it's time, Mom. Kate's ready. (Mom - That's not true. Kate would have told me.”) Jesse tells mom, “Mom, she did tell you,” and dad says, “She did. She told you a million times. You didn't wanna hear it.”

Sibling:

Anna: Large role in saving sister's life, pressure from family to save life and from sister to help her die, has to grow up and mature quickly because of her medical involvement in Kate's care

6:50-8:43 (Anna goes to see lawyer): "I want to sue my parents for the rights to my own body. My sister has leukemia. They're trying to force me to give her my body parts." (lawyer – "You're supposed to give her a kidney?") "She's been in renal failure for months now." (No one can force you to donate if you don't want to, can they?) "They think they can. I'm under 18, they're my legal guardians...they've been doing it to me my whole life. I wouldn't even be alive if Kate wasn't sick. I'm a designer baby. I was made in a dish to be spare parts for Kate. (Lawyer - The kid wasn't lying. The doctors started taking things from her the moment she was born. Cord blood as an infant, white-cell transfusions, bone marrow, lymphocytes, injections to add more stem cells, and then they took them too. But it was never enough. You do know what will happen if you don't give your sister your kidney, don't you?)" "Yeah, she'll die."

Mom gets served papers and Anna tells her I don't want to do it anymore mom, and mom gets really angry, slaps her on the face, tells her to remember it's her sister.

Parents sit down to talk with Anna (aunt and brother there too): Mom just can't accept her decision, but she says she doesn't want to give her kidney and have to careful her whole life after and that she's already lived a life very different from all the other kids, mom tells her, "You spoiled shit!" Anna yells at them, "who wants to live like that? I'm important too, mom. I'm important too."

(Anna calls sister during trial): Kate looks very sick, bruises all over head; Anna tells her, "I don't think I can do this anymore." Kate urges her on. (Anna has to endure her parents and others being angry and disappointed at her to try to help her sister achieve her wishes)

1:18:00-1:18:21: Mom's statement during court hearing: "Anna isn't the only person in this equation. And if we were looking at it only from Anna's situation, sure, it is brutal. I mean, who wants to be stuck and poked and prodded by needles? And you can look at me and you can say how awful I am for doing that to my child. You know what? It is awful. But it's not as awful as putting your child in the ground. You stand up for your family. It's my job." (Lawyer – "And you stand up for Kate.") I do. (Lawyer – "But the real question is: Who stands up for Anna?").

**The scene where Kate calls out for her "sissy" and Anna has to do what seems to be rolling her over and cleaning the stool from under her / on her, really exemplifies the parentification of Anna. Also, the scene where Anna finds Kate a drunk mess in her room and Kate alludes to wanting to kill herself reveals the stress Anna endures.

Jesse: Isolated, not involved in medical care, looks on from a distance frequently, his problems are neglected like his dyslexia, left alone frequently

Kate: "While everyone was so worried about my blood counts, they barely even noticed that Jesse was dyslexic. (go to a scene in the past where parents sitting with Jesse telling him about camp with special teachers for him, he tells them he'll try harder, parents explain to him that things are just mixed up in his head and the camp will help, he cries and agrees to it) I'm sorry, Jesse. I'm sorry I took all the attention when you were the one who needed it the most."

37:13-38:40: Jesse comes home and whole house is empty, see that he's really been left out, he takes a bus by himself, and walks around town alone. (he walks around the bad part of town, sitting on dangerous street corners, completely lost or forgotten)

Jesse was gone all day and came back late at night because he missed the bus, no one noticed, dad just asked him if we wanted to go spend the night at the hospital with Kate.

Poignant scene during the court case toward the end of the movie just before Kate's death where Jesse stands precariously on the edge of the roof of the courthouse and rips a watercolor of his sister up and lets the wind take the pieces...one of his legs bends suddenly as if he might fall/jump but he doesn't.

Family:

Aunt Kelly switches to working part time once Kate becomes sick to help out the family.

(Everyone at the hospital with Kate): Brother talking says, "Nobody's saying anything but seeing everybody together lets me know that this is serious. Our family is kind of disconnected. Dad's relatives are wealthy and distant, and Mom's side drives her crazy. So besides Aunt Kelly, we never really get to see anybody except on holidays or disasters." (distant family not really involved and when they come, don't understand the severity of the situation)

Financial: Not much stress apparent. Dad is firefighter but comes from money. Mom was an attorney but quit job to stay at home and help take care of Kate. Mom's sister helps to take care of the household. They are able to afford a boarding school for son's dyslexia.

School: No mention of school or home tutoring for Kate.

Living Situation: No stress, nice home environment.

Social: No directly discussed, but Kate not shown to have many interactions with people of her age. Most social interaction is with family, and then with Taylor for some time. Gets to go to prom-like event at the hospital which is main young social scene shown.

Sources of Psychosocial Support:

Internal, Non-Professional Psychosocial Supports (Nuclear and Close Family):

Mother: Main support for Kate, pushes Kate to fight (not always in most successful way)

23:35-24:31: Kate in bed in her room unwilling to get up, mom very strict with her, yells at her that she can do it, that it's a beautiful day outside, that she has to get up." When Kate tells her "No, I'm too sick," mom tells her, "You're not too sick. You're depressed. I'm not gonna feed you antidepressants because they're gonna just make you more numb than you already are. Now, get up." When they continue to ask her what's really wrong, she yells at them while crying, "I'm tired. Don't you get that? I'm sick, and I'm tired, and I'm ugly. (mom – Stop it!) Don't you dare tell me that I'm beautiful, because I'm not. Don't you dare tell me that nobody's gonna stare at me, because they will. I'm a freak." Mom tells her that's it and shaves her head too. (After, they go out to park and both mom and Kate walk around without a hat)

Taylor dies and mom stays with Kate caressing her and helping her get through it.

1:32:58-1:36:36 (Mom and Kate talk after mom finds out truth about the trial): Kate – "You don't wanna talk?" Mom – "Nope." Kate – "Are you mad at me?" Mom – "I'm not mad at you, I'm just mad. You gotta get some rest, okay? You be strong for surgery." Kate shows her the scrapbook she made for her mom, tells her it's everything, it's us. Her and mom talk about their memories. Kate caresses mom and tells her, "It's going to be okay." Mom starts crying and Kate holds her in her arms and they lie in the bed together. (Mom has stood by Kate throughout her illness, and now Kate is providing support to mom to help her cope with her own death which she has accepted)

Father: Depicted as the more understanding parent who is on the same page as Kate with her understanding of her illness and death. More of a listener compared to mom who is a fighter and doer and pushes Kate, whereas dad takes time to listen to what Kate wants. He takes her to the beach for a day, and Kate returns to the hospital the happiest she has been in the movie.

Anna: Very big support to Kate, one of few people who listens to Kate's wishes at end-of-life, helps her get through many hospitalizations

34:17-35:05: go back to image of girls playing together in hospital with mean nurse coming in and yelling at Kate to give urine sample now, girls call her a "bitch" and girls play a joke on her, and nurse tells them they're disgusting (nurse portrayed as mean and unable to take a joke)

1:24:33-1:26:15 (Anna taking care of Kate in bed and cleaning her up): Kate – "Don't worry. It's just the new medicine getting ready for the kidney." Anna – "You in pain?" Kate – "Pain? My whole life is a pain. This is the end, sissy. It just gets scarier from here on out. Mom's gonna chop me and cut me till I'm a vegetable. Two cells in a Petri dish that she shocks with an electric cord." Anna – "You'll be all right." Kate – "It's over. Time to go. I need you to do me a favor, sissy. You can release me." (both crying) – (Kate is only person that seems strong enough to listen to Kate's concerns and wishes, and provide support for her decisions)

1:26:44-1:28:25 (another scene with Anna and Kate discussing how to go about trial, lying on a blanket in a field): When Ana says they're never gonna believe me, Kate tells her, "Yeah, they will. And you wanna know why? Because it's the truth." Anna asks her, "You scared?" and Kate tells her, "No. I know I'll be okay." Anna – "What do you think happens? I mean, where do you go?" Kate, "I don't know, baby. Wherever it is, maybe I'll run into Taylor." Anna – "Will you wait for me? If you go anywhere crazy, will you wait? I mean, how will I know how to find you?" (Anna starts crying). Kate tells her, "If you're ever lost or scared, go to Montana. That's where I'll be."

Jesse: While often isolated and neglected, still provides support to Kate, staying at the hospital with her, cheering her up, and keeping her and Anna's secret about the court hearing. He feels the burden of being someone who understands everyone's views and wishes and is in the middle of all of the discord without having much say about what will happen.

Aunt: Huge support to family through Kate's sickness, helps take care of household, supports mom and Kate and is there for them to listen to their concerns and wishes.

1:04:45-1:05:35: Aunt tries to talk with Sara about fighting Anna's wishes: she tells her, "I'm behind you, no matter what. I'll do whatever, and I do. I'm just not sure you're seeing the big picture. I know it's important for you to feel like you never gave up. I mean, who are you if you're not this crazy bitch mother fighting for her kid's life, right? But there's, like, a whole world out there. You don't see any of it, nothing. Sooner or later, you gotta stop. You gotta let go." Sara tells her, "I can't."

Extended family: Are at the hospital whenever the situation is serious but don't provide the best support as they don't understand the situation fully.

1:29:20-1:32:00 (extended family comes to see Kate): they tell her things like, "Hey, you look good. You do...Look, I got you this book, okay? It's full of guided meditations, visualizations, healing stuff. Really good for you, okay...Keep fighting. A lot of living to do, okay? All right, promise me?" Another family member continues to tell her, "You've just gotta tell yourself you're gonna get better. Tell your brain to heal yourself and work on it while you're sleeping. I'm not kidding. Subconscious mind is a really powerful thing," and someone else adds, "Yeah, you know, it's like this lady I saw on TV. She would talk to her cancer cells and ask them to go away. And eventually they did. I did not make this up, this is true. Go away, cancer cells. Yeah, like that. Speaking more sincerely than that." After a few more stories, woman says, "Miracles happen every day. That's right. This world isn't made up of science and medicine. There are powerful things out there that none of us can understand." As everyone is talking, see Kate, her parents,

Anna and Jesse just looking and not participating, you see that no one else really understands what is going on but them. Kate sends everyone home, says she needs some time with mom.

External Non-Professional Psychosocial Supports (Significant others, friends, clergy, coaches, teachers, etc.):

Taylor, another child with leukemia who becomes her boyfriend:

43:00-45:11: Go to prior time when Kate meets a boy, Taylor with AML, and they talk about their disease (understand each other and vocabulary), mom is happy for her.

Mom talks about her meeting Taylor: “The radiation, which ultimately put Kate into remission worked its magic by wearing her down. Taylor Ambrose, a drug of an entirely different sort worked his magic by building her up.”

48:05-48:45: When Taylor and Kate kiss, she tells him she can taste his cytoxan, and then she tells him she likes it, “Besides they told me yesterday, I'm relapsing. I start chemo next week. Maybe it'll save me a dose.” He hugs her after and holds her. (he is one of few people who truly understands what she is going through and how to best support her)

After, Kate immediately goes and wakes Anna up to tell her about the kiss and they talk like sisters and lie in bed together. Kate tells Anna that he has scars on his hands from graft-versus-host that she could feel them when they were holding hands. “It was kind of like we matched.”

51:00-54:18: Taylor in hospital with Kate, taking care of her when she's vomiting after starting chemo again. When she apologizes, he says, “What are you talking about. Tomorrow it could be me.” He gives her gum and water and holds her. Hospital throws a dance for sick kids with band, tuxes, etc., and he asks her to go with him.

59:20-1:00:07: Kate asks Taylor, “You ever think about dying? (Not really.) You're not scared? (No. If I didn't have cancer, I never would have found you. So yeah, I'm glad I'm sick.) Me too. (You okay?) Yeah.” (She can talk with him about death).

Professional Medical Supports (Oncologists, Nurses, Specialists):

Dr. Farquad (oncologist): Shown mostly initially in presentation of the diagnosis. She is very matter-of-fact, but is still compassionate although does not appear to get to know the family as much as Dr. Chance.

Dr. Chance (oncologist): Long-term relationship with Kate and her family. He is one who suggested having Anna. He seems to have a close relationship with Kate, and is first person to advocate for her wishes to her parents. Attempts to involve end-of-life care when appropriate. Attempts to provide support to parents and to Kate, but clearly there for Kate primarily.

Dad goes to see Kate, nurse tells him she's been talking about going to the beach all day, dad talks with Dr. Chance and tells him that she wants to go, and Dr. Chance finds a way to make it happen, “It's one day. Kate's been through the wringer, so if it's not gonna make her any worse, I say take the kid to the beach.” (Dr. Chance shows compassion and desire to care for his patients holistically, returns to hospital late at night to re-admit her after her trip)

Nurses: One mean nurse shown in scene where Kate and Anna play joke on her with urine sample and she calls them disgusting. Kate shown interacting in a friendly manner with nurse in infusion room, asking her opinion on Taylor when she meets him.

Professional Psychosocial Supports (Social work, child life, psychologist, psychiatrist, mental health nurse, chaplain/clergy in hospital, palliative care professional):

40:22-41:56 (Dr. Chance introduces mom to home health aide, Miss Swearingen, palliative care specialist): They stand outside room talking, aid asks mom if she's spoken to the Make-A-Wish people and tell her that she might want to consider taking Kate home, making her comfortable, managing her pain. Mom will not hear any of this, calls it the "quality of life speech," tells them no hospice care, asks them "you think we should take Kate home to die?" Doctor tells her, "It's an option. Look, I know you don't listen to anybody, but it's our job to tell you," and home health aid says, "Death is a normal process of life. You need to acknowledge that." Mom continues to be angry, asks doctor, "who is this broad?" in reference to the home health aide. Aide asks her, "Have you spoken to Kate? You know what she wants?" Mom says, "I don't care what anybody wants. We're doing the operation," and doctor tells her, "What operation, Sara? You have an unwilling donor. The hospital won't even allow it anymore without a court order. You think we don't know what's going on here?" Aide says, "Your daughter is dying, and you might want to spend some quality time with her." Kate looks at mom angry and yelling at the doctor and aide through her room window.

Stigma:

About Cancer: Ignorant extended family visits with Kate shortly before death and advise her to just try a little harder and she could make it go away...mind over body idea...tell stories of prior miracles and that they can happen to her (1:30:47-1:31:44)

About psychiatric/psychosocial aspects: Mom to Kate: "You're not too sick. You're depressed. I'm not gonna feed you antidepressants because they're gonna just make you more numb than you already are. Now, get up."

About treatment team:

Ethical Dilemmas:

Having a genetically engineered child to help save another child, informed consent for Anna:

Opening scene: Anna tells us about making babies and how they're usually coincidences and accidents. "I was engineered, born for a particular reason. A scientist hooked up my mother's eggs and father's sperm to make up a specific combination of genes. He did it to save my sister's life. Sometimes I wonder what would have happened if Kate would have been healthy? But coincidence or not, I'm here."

14:02-15:50 (parents meet with doctor in past to discuss transplant, this is the discussion where they consider having Anna): neither of the parents are a match and doctor explains to them that parents matching is a very rare occurrence, parents ask about Jesse and he's not either, doctor tells them, "It's possible that a donor will crop up on the national bone-marrow registry...Kate's situation is time-sensitive, and sometimes that's all we've got...I'd like to suggest something completely off the record. Many times one sibling isn't a match, but another is. Have you considered having another child? Not to be forward but umbilical blood can be an incredibly effective tool in treating leukemic patients. It's like a miracle." Parents ask, "Well, how would you know that the new child would be a match?" and he tells them, "We could make sure of it. With preimplantation genetic diagnosis, it would be a 100 percent match." Parents ask again, "A donor child?" He tells them, "It's not for everybody. And legally, I can't even officially recommend it. But like I said, cord blood would be invaluable." Mom says, "Well, we gotta do it. We gotta try." (young Jesse going to all these doctors visits with parents)

Dad thinks about Anna's life: "From the moment we decided to genetically conceive, I suppose this was the eventual outcome. It was our fault. We went against nature and this was our comeuppance. But have we really pushed her too hard? Have we forced her into helping her sister? All those little encouragements and rewards, were they real? Or did we just want what we wanted? She was so little when all this started. When

did she start wanting to make her own decisions? I guess the answer is now.” (20:17-20:28) Image of Anna screaming when she’s younger as they take her into a procedure.

22:34-23:34 (Sara sees lawyer who reminds her of what has happened to Anna): “Eight hospitalizations in 11 years, six catheterizations, two bone-marrow aspirations, two stem-cell purges. (Mom - She was helping her sister.) Not to mention the side effects, including bleeding, infections, bruising. Filgrastim shots. Those are growth hormones, am I correct? Drugs for nausea, opiates for pain, Ambien for sleep. Not exactly the proper medication for a preteen. (mom - Every procedure had its risks and complications. Anna understood that, she was okay with it.) Really? At 5 years old.”

Hearing: Anna tells us, “The court calls Dr. Kenny Chow. The doctors talked for what seemed like forever. They said that Kate was a miracle. She should have never made it past 5 years old. They talked about the psychological benefits of donation and how losing my kidney would affect the quality of my life. They all said that nothing was their fault, and it was a very complex problem. When put to the test most everyone thought that I should give Kate my kidney. But they also said that I was too young to understand the situation fully. And none of them could say at what age I would be able to understand. All in all, they were like me, pretty confused.”

Specific Themes Identified

Cancer as horror show (multiple scenes of Kate very sick, bleeding, everyone scared, intense scene where mom shaves her head as well, Kate getting drunk); saved by love; friends only with other sick kids; palliative care is giving up and quitting; parental grief; anticipatory grief; sibling isolation/neglect; leave no stone unturned; physical changes from illness → low self-esteem; denial about death; parental discord about treatment goals and prognosis; donor sibling; engaging in risky behavior because you’re sick; social isolation.

General Notes:

Reactions to Kate’s death:

Anna after Kate’s death: “My sister died that night. I wish I could say that she made some miracle recovery but she didn’t. She just stopped breathing. And I wish I could tell you that there was some good that came out of it, that through Kate’s death we could all go on living. Or even that her life had some special meaning like they named a park after her, or a street or that the Supreme Court changed a law because of her, but none of that happened. She’s just gone, a little piece of blue sky now. And we all have to move on.”

Anna tells us at the end: “Life is different now. A lot has changed in the last few years. Mom went back to work, rebuilt her practice and is now making a very nice living. Dad took an early pension and now spends time counseling troubled inner-city youths. And Jesse’s doing best of all. After Kate died, he turned his life around. He went back to school and got himself a scholarship to a fancy art academy in New York. And even though we’ve grown up and moved away, every year, on Kate’s birthday, we all take a vacation together and it’s always to the same place. I’ll never understand why Kate had to die and we all got to live. There’s no reason for it, I guess. Death’s just death, nobody understands it. Once upon a time, I thought I was put on Earth to save my sister. And in the end, I couldn’t do it. I realize now that wasn’t the point.

The point was, I had a sister. She was fantastic. One day, I’m sure I’ll see her again. But until then our relationship continues.”

Primary Notes While Watching Movie:

Opening scene: Anna tells us about making babies and how they’re usually coincidences and accidents. “I was engineered, born for a particular reason. a scientist hooked up my mother’s eggs and father’s sperm to make up a specific combination of genes. He did it to save my sister’s life. Sometimes I wonder what would have happened if Kate would have been healthy? But coincidence or not, I’m here.”

Anna outside playing and talking about Montana with Kate, seem to have a close relationship.

Anna introduces us to the rest of the family. “Since my sister got sick, things have changed, my aunt works part time and my mom quit her job as a lawyer...her life now revolves around keeping Kate alive, cooking and cleaning,” she tells us everything has to be organic, clean, and germ free; Anna tells us that her family may be dysfunctional but they love each other and do the best they can.

See everyone eating dinner together at the dinner table, telling jokes, mom obsessed at dinner over Kate not eating enough, then see whole family outside playing and jumping on trampoline, blowing bubbles

5:10-5:35 (Dad’s voice): “Having a child who is sick is a full-time occupation. Sure, we still enjoy the usual day-to-day happinesses of family life. Big house, great kids, beautiful wife. But beneath the exterior, there are cracks...resentments...alliances that threaten the very foundation of our lives...as at any moment our whole world could come tumbling down.”

5:42-6:15 (Sister gets sick with fever): Anna goes to find her and sees her in bathroom with bloody nose, coughing, looks embarrassed and angry.

6:50-8:43 (Anna goes to see lawyer): “I want to sue my parents for the rights to my own body. My sister has leukemia. They're trying to force me to give her my body parts.” (lawyer – “You're supposed to give her a kidney?”) “She's been in renal failure for months now.” (No one can force you to donate if you don't want to, can they?) “They think they can. I'm under 18, they're my legal guardians...they've been doing it to me my whole life. I wouldn't even be alive if Kate wasn't sick. I'm a designer baby. I was made in a dish to be spare parts for Kate. (Lawyer - The kid wasn't lying. The doctors started taking things from her the moment she was born. Cord blood as an infant, white-cell transfusions, bone marrow, lymphocytes, injections to add more stem cells, and then they took them too. But it was never enough. You do know what will happen if you don't give your sister your kidney, don't you?)” “Yeah, she'll die.”

9:45-10:18 (Mom takes Kate to doctor long time ago because she’s always tired and see a big bruise on her back): Doctors room with lots of toys; doctor sit with mom in her office later and tells her, “Kate's white cell count's much lower than normal...She may have an autoimmune deficiency. Could just be a lab error.” Gives her card for oncologist, and she says, “Oncology? But that's cancer.”

10:25- (Parents meet with oncologist, Dr. Farquad): She sits down next to them in the waiting room and immediately starts telling them, “So I took a look at Kate's CBC. Her white blood count is very low. She's also presenting with 12% promyelocytes and 5% blasts which does indicate a leukemic syndrome.” (Parents asks “Leukemic?”) Dr. Farquad tells them “Cancer. I'll need a bone marrow aspiration to confirm but it seems that Kate could have what is called acute promyelocytic leukemia. I'm sorry.” (parents immediately start crying)

10:51-11:15: Kate gets bone marrow aspiration as mom watches through the window, no one has explained anything to Kate yet.

Parents discuss diagnosis after: Dad says “St. Joe's doesn't know shit. You remember when the chief's son was playing with Jesse and broke his left arm? They put a cast on his right,” and wife tells him, “I'm not gonna let her die. You know that, right? I'm not.”

12:30-13:00 (Katie gets very sick and doesn’t want to open door to let anyone help her, mom had to kick door down): Siblings run in to see and they look terrified as does Kate herself as EMT puts her on stretcher): During scene, there’s a lot of blood, mom tells them that they need to get platelets and fluid into her because she doesn’t want her going into shock. Mom tells them she’s 15, about 90 pounds, she's allergic to penicillin (mom seems to know the medical information well and knows the drill) (Everyone at the hospital with Kate): Brother talking says, “Nobody's saying anything but seeing everybody together lets me know that this is serious. Our family is kind of disconnected. Dad's relatives are wealthy and distant, and Mom's side drives her crazy. So besides Aunt Kelly we never really get to see anybody except on holidays or disasters.”

13:20-14:00 (doctors come to tell family news about prognosis): two doctors come and sit in circle with whole family, “Kate's leukemia is back. She's no longer remissing. We've looked at her smear, and her leukemic cells are showing at 23%. (How many is bad?) Any. (What about chemo?) It's an option, but Kate doesn't seem to take it very well. And her cancer may be too far along. (So you need more bone marrow?) Yes, but the leukemia isn't Kate's biggest problem now. She's lost the function of her kidneys. They've quit. They're gone.” (doctors seem compassionate)

14:02-15:50 (parents meet with doctor in past to discuss transplant, this is the discussion where they consider having Anna): neither of the parents are a match and doctor explains to them that parents matching is a very rare occurrence, parents ask about Jesse and he’s not either, doctor tells them, “It's possible that a donor will crop up on the national bone-marrow registry...Kate’s situation is time-sensitive, and sometimes that's all we've got...I'd like to suggest something completely off the record. Many times one sibling isn't a

match, but another is. Have you considered having another child? Not to be forward but umbilical blood can be an incredibly effective tool in treating leukemic patients. It's like a miracle." Parents ask, "Well, how would you know that the new child would be a match?" and he tells them, "We could make sure of it. With preimplantation genetic diagnosis, it would be a 100 percent match." Parents ask again, "A donor child?" He tells them, "It's not for everybody. And legally, I can't even officially recommend it. But like I said, cord blood would be invaluable." Mom says, "Well, we gotta do it. We gotta try." (young Jesse going to all these doctors visits with parents)

Brother after tells us, "That was it. Grown in a dish, they would have an in vitro child. A perfect chromosomal match who would be Kate's genetic savior."

Mom gets served papers and Anna tells her I don't want to do it anymore mom, and mom gets really angry, slaps her on the face, tells her to remember it's her sister.

Parents sit down to talk with Anna (aunt and brother there too): Mom just can't accept her decision, but she says she doesn't want to give her kidney and have to careful her whole life after and that she's already lived a life very different from all the other kids, mom tells her, "You spoiled shit!" Anna yells at them, "who wants to live like that? I'm important too, mom. I'm important too."

Dad thinks about Anna's life: "From the moment we decided to genetically conceive, I suppose this was the eventual outcome. It was our fault. We went against nature and this was our comeuppance. But have we really pushed her too hard? Have we forced her into helping her sister? All those little encouragements and rewards, were they real? Or did we just want what we wanted? She was so little when all this started. When did she start wanting to make her own decisions? I guess the answer is now." (20:17-20:28) Image of Anna screaming when she's younger as they take her into a procedure.

22:34-23:34 (Sara sees lawyer who reminds her of what has happened to Anna): "Eight hospitalizations in 11 years, six catheterizations, two bone-marrow aspirations, two stem-cell purges. (Mom - She was helping her sister.) Not to mention the side effects, including bleeding, infections, bruising. Filgrastim shots. Those are growth hormones, am I correct? Drugs for nausea, opiates for pain, Ambien for sleep. Not exactly the proper medication for a preteen. (mom - Every procedure had its risks and complications. Anna understood that, she was okay with it.) Really? At 5 years old."

23:35-24:31: Kate in bed in her room unwilling to get up, mom very strict with her, yells at her that she can do it, that it's a beautiful day outside, that she has to get up." When Kate tells her "No, I'm too sick," mom tells her, "You're not too sick. You're depressed. I'm not gonna feed you antidepressants because they're gonna just make you more numb than you already are. Now, get up." When they continue to ask her what's really wrong, she yells at them while crying, "I'm tired. Don't you get that? I'm sick, and I'm tired, and I'm ugly. (mom - Stop it!) Don't you dare tell me that I'm beautiful, because I'm not. Don't you dare tell me that nobody's gonna stare at me, because they will. I'm a freak." Mom tells her that's it and shaves her head too. (After, they go out to park and both mom and Kate walk around without a hat)

25:38-28:54 (Kate talking as she looks through her scrapbook): "This is it. I know I'm going to die now. I suppose I've always known that. I just never knew when. And I'm okay with it. Really. I don't mind my disease killing me. But it's killing my family too. While everyone was so worried about my blood counts, they barely even noticed that Jesse was dyslexic. (go to a scene in the past where parents sitting with Jesse telling him about camp with special teachers for him, he tells them he'll try harder, parents explain to him that things are just mixed up in his head and the camp will help, he cries and agrees to it) I'm sorry, Jesse. I'm sorry I took all the attention when you were the one who needed it the most. Dad, I know I took your first love from you. I only hope that one day, you get her back. Mom, you gave up everything for me. Your work, your marriage, your entire life just to fight my battles for me every single day. I'm sorry you couldn't win. And to my baby sis, who was always so very little, I'm sorry I let them hurt you. I'm sorry I didn't take care of you. It was supposed to be the other way around."

Trial: Mom telling judge, "Anna's too young to make a decision of this size on her own. She doesn't understand what it is she wants. She's 11 years old. She changes her mind every five minutes. You know how young girls can be." Counselor wants to talk with Anna herself and tells Sara before she leaves, "I'm awfully sorry about Kate." Anna tells the counselor, "I don't like everyone being mad at me," she says that she doesn't mind having to take care of her sister all the time." (go back to image of girls playing together in hospital with mean nurse coming in and yelling at Kate to give urine sample now, girls call her a "bitch" and girls play a joke on her, and nurse tells them they're disgusting (34:17-35:05); Kate cries after remembering this). Counselor tells Anna, "There's no shame in dying."

37:13-38:40: Jesse comes home and whole house is empty, see that he's really been left out, he takes a bus by himself, and walks around town alone.

38:50-40:21 (mom and aunt in Kate's hospital room, chatting and laughing): Doctor comes in and asks her the pain level and she tells him 6 and he says all right, let's take care of that. He then talks to mom in the corner of the room in hushed voices and when mom says "She's feeling pretty good today," he tells her, "Sara, these lucid moments are gonna get briefer and further apart. Kate's in system failure now. Body defenses are at zero. The fevers Kate's been getting, it's infection from the dialysis. And it's not just in her arm or leg, it's in her blood. I'm sorry, Sara, this is it. We're at the end." Kate is looking on, looks sad, and calls to Dr. Chance, he tells her, "What is it, princess?" and walks over and sits by her, she says, "No good, huh?" He tells her no and when she asks how long, he says, "It's hard to say. But if nothing changes, not too long." Kate's eyes fill with tears, mom immediately comes in and says, "Not too long? Not too long what?" Kate continues asking questions, "Will it hurt?" and doctor tells her, "No. I'll make sure of that." Mom again jumps in and says strictly, "Listen, I don't wanna hear talk like that, okay, honey? You just stay strong enough for surgery, okay?" Kate says, "Okay, Mom," to please her as her aunt hold her hand and kisses her. Dr. Chance asks mom to step outside with him.

40:22-41:56 (Dr. Chance introduces mom to home health aide, Miss Swearingen): They stand outside room talking, aid asks mom if she's spoken to the Make-A-Wish people and tell her that she might want to consider taking Kate home, making her comfortable, managing her pain. Mom will not hear any of this, calls it the "quality of life speech," tells them no hospice care, asks them "you think we should take Kate home to die?" Doctor tells her, "It's an option. Look, I know you don't listen to anybody, but it's our job to tell you," and home health aid says, "Death is a normal process of life. You need to acknowledge that." Mom continues to be angry, asks doctor, "who is this broad?" in reference to the home health aide. Aide asks her, "Have you spoken to Kate? You know what she wants?" Mom says, "I don't care what anybody wants. We're doing the operation," and doctor tells her, "What operation, Sara? You have an unwilling donor. The hospital won't even allow it anymore without a court order. You think we don't know what's going on here?" Aide says, "Your daughter is dying, and you might want to spend some quality time with her." Kate looks at mom angry and yelling at the doctor and aide through her room window.

43:00-45:11: Go to prior time when Kate meets a boy, Taylor with AML, and they talk about their disease (understand each other and vocabulary) and then he gets her phone number. After he leaves, she asks nurse what she thinks and nurse tells her he's fine, he calls her right away, mom is happy for her.

Mom talks about her meeting Taylor: "The radiation, which ultimately put Kate into remission worked its magic by wearing her down. Taylor Ambrose, a drug of an entirely different sort worked his magic by building her up."

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Kate immediately goes and wakes Anna up to tell her about the kiss and they talk like sisters and lie in bed together. Kate tells Anna that he has scars on his hands from graft-versus-host that she could feel them when they were holding hands.

"It was kind of like we matched."

51:00-54:18: Taylor in hospital with Kate, taking care of her when she's vomiting after starting chemo again. When she apologizes, he says, "What are you talking about. Tomorrow it could be me." He gives her gum and water and holds her. Hospital throws a dance for sick kids with band, tuxes, etc., and he asks her to go with him.

See her go dress shopping with all the girls in her family, and she gets angry because she doesn't look good, and wants to cover up her head, she ends up buying a wig and looks beautiful for the dance (whole family so excited, taking pictures of her, looks like normal family getting ready for prom)

59:20-1:00:07: Kate asks Taylor, "You ever think about dying? (Not really.) You're not scared? (No. If I didn't have cancer, I never would have found you. So yeah, I'm glad I'm sick.) Me too. (You okay?) Yeah." (She can talk with him about death).

Taylor dies and mom stays with Kate caressing her and helping her get through it. (Last time she saw him was the hospital prom)

Jesse was gone all day and came back late at night, no one noticed, dad just asked him if we wanted to go spend the night at the hospital with Kate.

1:04:45-1:05:35: Aunt tries to talk with Sara about fighting Anna's wishes: she tells her, "I'm behind you, no matter what. I'll do whatever, and I do. I'm just not sure you're seeing the big picture. I know it's important for you to feel like you never gave up. I mean, who are you if you're not this crazy bitch mother

fighting for her kid's life, right? But there's, like, a whole world out there. You don't see any of it, nothing. Sooner or later, you gotta stop. You gotta let go." Sara tells her, "I can't."

Dad goes to see Kate, nurse tells him she's been talking about going to the beach all day, dad talks with Dr. Chance and tells him that she wants to go, and Dr. Chance finds a way to make it happen, "It's one day. Kate's been through the wringer, so if it's not gonna make her any worse, I say take the kid to the beach."

1:08:36-1:09:34: Dad picks up other kids from school and gets everyone together to take her to the beach, mom freaks out about it and yells at dad, "I don't give a shit who you talked to! You are killing her! You understand? Take her to the beach, you kill her!" Kate starts crying, mom tells him, "See how upset she is? See what you're doing? I'll call cops. He tells her, "Do what you gotta do. - Last 14 years I've let you have it your way. Last 14 years have been about saving her!

Today is not about you. It's about Kate. She wants to go to the beach." Mom keeps yelling that she will die and dad says if she doesn't come he'll get a divorce. (mom eventually joins them at the beach)

Back at hospital, Dr. Chance meets them in the ED smiling, and Kate is the happiest we've seen her in a long time.

Hearing: Anna tells us, "The court calls Dr. Kenny Chow. The doctors talked for what seemed like forever. They said that Kate was a miracle. She should have never made it past 5 years old. They talked about the psychological benefits of donation and how losing my kidney would affect the quality of my life. They all said that nothing was their fault, and it was a very complex problem. When put to the test most everyone thought that I should give Kate my kidney. But they also said that I was too young to understand the situation fully. And none of them could say at what age I would be able to understand. All in all, they were like me, pretty confused."

(Anna calls sister during trial): Kate looks very sick, bruises all over head; Anna tells her, "I don't think I can do this anymore." Kate urges her on.

Lawyer questions Sara about the lymphocyte donation, granulocyte donation, bone-marrow aspiration and what that meant Anna had to go through.

1:18:00-1:18:21: Jesse is sitting over the edge of the court room building, stands up on ledge, lets papers fly off.

Mom's statement during court hearing: "Anna isn't the only person in this equation. And if we were looking at it only from Anna's situation, sure, it is brutal. I mean, who wants to be stuck and poked and prodded by needles? And you can look at me and you can say how awful I am for doing that to my child. You know what? It is awful. But it's not as awful as putting your child in the ground. You stand up for your family. It's my job." (Lawyer – "And you stand up for Kate.") I do. (Lawyer – "But the real question is: Who stands up for Anna?").

1:20:24-1:24:00 (Anna called to witness stand): Mom questions her, "You love your sister, right? You know she's sick. Why won't you help her?" (go to scene of Anna finding Kate drunk in her room having a going-away party by herself, breaking everything in her room, taking pills, and Kate yells no) Jesse interrupts during the trial and questions Anna if medical emancipation is really all that they're here about. Mom tells Anna that it doesn't add up and that she's hiding something, "People give their kidneys to total strangers. You'd better start talking right now. You're not telling the truth, because if you are, I don't know you." Jesse starts yelling for Anna to tell the truth, and finally Jesse yells out, "God, you people are so stupid! Kate wants to die! She's making Anna do all this because she knows she's not gonna survive. (Mom - That's a lie, Jesse!" Oh, no, it's not! Kate's dying and everybody knows it. You just love her so much that you don't want to let her go. But it's time, Mom. Kate's ready. (Mom - That's not true. Kate would have told me.") Jesse tells mom, "Mom, she did tell you," and dad says, "She did. She told you a million times. You didn't wanna hear it."

1:24:33-1:26:15 (Anna taking care of Kate in bed and cleaning her up): Kate – "Don't worry. It's just the new medicine getting ready for the kidney." Anna – "You in pain?" Kate – "Pain? My whole life is a pain. This is the end, sissy. It just gets scarier from here on out. Mom's gonna chop me and cut me till I'm a vegetable. Two cells in a Petri dish that she shocks with an electric cord." Anna – "You'll be all right." Kate – "It's over. Time to go. I need you to do me a favor, sissy. You can release me." (both crying)

1:26:44-1:28:25 (another scene with Anna and Kate discussing how to go about trial, lying on a blanket in a field): When Ana says they're never gonna believe me, Kate tells her, "Yeah, they will. And you wanna know why? Because it's the truth." Anna asks her, "You scared?" and Kate tells her, "No. I know I'll be okay." Anna – "What do you think happens? I mean, where do you go?" Kate, "I don't know, baby. Wherever it is, maybe I'll run into Taylor." Anna – "Will you wait for me? If you go anywhere crazy, will

you wait? I mean, how will I know how to find you?" (Anna starts crying). Kate tells her, "If you're ever lost or scared, go to Montana. That's where I'll be."

Judge goes to see Kate in hospital, right before see two doctors talking to mom telling her, "It's hard to say. It takes from anywhere between 24 and 48 hours or so." Whole family sitting together in waiting room.

1:29:20-1:32:00 (extended family comes to see Kate): they tell her things like, "Hey, you look good. You do...Look, I got you this book, okay? It's full of guided meditations, visualizations, healing stuff. Really good for you, okay...Keep fighting. A lot of living to do, okay? All right, promise me?" Anna and Jesse walk over to her, apologize for telling on her, she tells Anna, "you know how brave you are?" and they hug and kiss each other. Another family member continues to tell her, "You've just gotta tell yourself you're gonna get better. Tell your brain to heal yourself and work on it while you're sleeping. I'm not kidding. Subconscious mind is a really powerful thing," and someone else adds, "Yeah, you know, it's like this lady I saw on TV. She would talk to her cancer cells and ask them to go away. And eventually they did. I did not make this up, this is true. Go away, cancer cells. Yeah, like that. Speaking more sincerely than that." After a few more stories, woman says, "Miracles happen every day. That's right. This world isn't made up of science and medicine. There are powerful things out there that none of us can understand." As everyone is talking, see Kate, her parents, Anna and Jesse just looking and not participating, you see that no one else really understands what is going on but them.

Kate sends everyone home, says she needs some time with mom.

1:32:58-1:36:36: Kate – "You don't wanna talk?" Mom – "Nope." Kate – "Are you mad at me?" Mom – "I'm not mad at you, I'm just mad. You gotta get some rest, okay? You be strong for surgery." Kate shows her the scrapbook she made for her mom, tells her it's everything, it's us. Her and mom talk about their memories. Kate caresses mom and tells her, "It's going to be okay." Mom starts crying and Kate holds her in her arms and they lie in the bed together.

Anna after Kate's death: "My sister died that night. I wish I could say that she made some miracle recovery but she didn't. She just stopped breathing. And I wish I could tell you that there was some good that came out of it, that through Kate's death we could all go on living. Or even that her life had some special meaning like they named a park after her, or a street or that the Supreme Court changed a law because of her, but none of that happened. She's just gone, a little piece of blue sky now. And we all have to move on."

Anna tells us at the end: "Life is different now. A lot has changed in the last few years. Mom went back to work, rebuilt her practice and is now making a very nice living. Dad took an early pension and now spends time counseling troubled inner-city youths. And Jesse's doing best of all. After Kate died, he turned his life around. He went back to school and got himself a scholarship to a fancy art academy in New York. And even though we've grown up and moved away, every year, on Kate's birthday, we all take a vacation together and it's always to the same place. I'll never understand why Kate had to die and we all got to live. There's no reason for it, I guess. Death's just death, nobody understands it. Once upon a time, I thought I was put on Earth to save my sister. And in the end, I couldn't do it. I realize now that wasn't the point. The point was, I had a sister. She was fantastic. One day, I'm sure I'll see her again. But until then our relationship continues."

C. Film Analysis Instrument – Blank

ChildrenNumber	<input type="text" value="37"/>	Diagnosis	<input type="text"/>	Cancer symptoms:	<input type="text"/>																				
MovieAssociationNumber	<input type="text" value="0"/>																								
Name	<input type="text"/>	Co-morbid illnesses	<input type="text"/>	Complications:	<input type="text"/>																				
Age	<input type="text" value="0"/>																								
Gender	<input type="text"/>																								
<p>Treatment</p> <input type="checkbox"/> Chemotherapy <input type="checkbox"/> Radiation therapy <input type="checkbox"/> Surgery <input type="checkbox"/> Bone marrow transplant <input type="checkbox"/> Experimental treatments <input type="checkbox"/> Palliative Care <input type="checkbox"/> Other treatments If yes: <input type="text"/> Treatment side effects: <input type="text"/>																									
<p>Diagnosis Discussion</p> Patient: <input type="text"/> Family: <input type="text"/> Treatment team: <input type="text"/> General diagnosis discussion effective?: <input type="text"/> Diagnosis notes:: <input type="text"/>		<p>Prognosis Discussion</p> Patient: <input type="text"/> Family: <input type="text"/> Treatment team: <input type="text"/> General prognosis discussion effective?: <input type="text"/> Prognosis notes:: <input type="text"/>		<p>Treatment Discussion</p> Patient: <input type="text"/> Family: <input type="text"/> Treatment team: <input type="text"/> General treatment discussion effective?: <input type="text"/> Treatment notes:: <input type="text"/>																					
<p>Outcome: <input type="text"/></p>																									
<p>Psychopathology</p> <input type="checkbox"/> Specific diagnoses? If yes, list: <input type="text"/> <input type="checkbox"/> Discussed with patient <input type="checkbox"/> Discussed with family <input type="checkbox"/> Discussed with treatment team <input type="checkbox"/> Psychiatric treatments If yes, list: <input type="text"/> General comments:: <input type="text"/>			<p>Psychosocial Stressors</p> Patient: <input type="text"/> Mother: <input type="text"/> Father: <input type="text"/> Siblings: <input type="text"/> Extended Family: <input type="text"/> General comments: <input type="text"/> <input type="checkbox"/> Finances <input type="checkbox"/> School <input type="checkbox"/> Social <input type="checkbox"/> Religious <input type="checkbox"/> Living situation																						
<p>Psychosocial Supports</p> <table border="1"> <thead> <tr> <th>Support Member#</th> <th>Patient#</th> <th>Patient Name</th> <th>Supporter category:</th> <th>Movie Name:</th> </tr> </thead> <tbody> <tr> <td>(New)</td> <td>37</td> <td></td> <td></td> <td></td> </tr> <tr> <td>Supporter name:</td> <td>Supporter title:</td> <td>Presence</td> <td>Involvement</td> <td>Efficacy</td> </tr> <tr> <td><input type="text"/></td> <td><input type="text"/></td> <td><input type="text" value="0"/></td> <td><input type="text" value="0"/></td> <td><input type="text" value="0"/></td> </tr> </tbody> </table>						Support Member#	Patient#	Patient Name	Supporter category:	Movie Name:	(New)	37				Supporter name:	Supporter title:	Presence	Involvement	Efficacy	<input type="text"/>	<input type="text"/>	<input type="text" value="0"/>	<input type="text" value="0"/>	<input type="text" value="0"/>
Support Member#	Patient#	Patient Name	Supporter category:	Movie Name:																					
(New)	37																								
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<p>Record: <input type="text"/> 1 of 1 <input type="text"/> No Filter <input type="text"/> Search</p>																									
<p>Themes: <input type="text"/></p>																									

D. Film Analysis Instrument – *My Sister's Keeper* (2009) Example

Title of Movie	Name	Age	Gender
My Sister's Keeper	Kate Fitzgerald	15	Female
Diagnosis			
Acute Promyelocytic Leukemia			
Cancer symptoms			
Bleeding (epistaxis, bruising, hemoptysis), fatigue, difficulty walking (in wheelchair at end)			
Complications			
Relapse; Organ failure			
Outcome	Chemotherapy	Radiation therapy	Surgery
Death	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Other Treatments:			
Cord blood transplant, white cell infusion, dialysis			
Treatment side effects			
Hair loss, immunosuppression (fever, coughing, sepsis), nausea/vomiting			
Diagnosis Discussed: Patient	Diagnosis Discussed: Family	Diagnosis Discussed: Treatment team	Diagnosis Discussed: Patient
NO	Yes	No	Yes
Prognosis Discussed: Family	Prognosis Discussed: Treatment team	General prognosis discussion effective?	Treatment Discussed: Family
Yes	Yes	Yes	Yes
Treatment Discussed: Treatment team	General treatment discussion effective?		
Yes	Yes		
Diagnosis notes:			
Dr. Farquard tells parents/child in waiting area, lots of medical lingo, little support after.			

Prognosis notes:	
Dr. Chance honest, compassionate, close relationship with Kate, understands family dynamics, attempts to involve everyone.	
Treatment notes:	
Limited explanations initially, more detail later, family/child knowledgeable, not on same page with rx goals	
Psychopathology- Specific diagnoses?	
<input checked="" type="checkbox"/>	
Psychopathology: If yes, list:	
Depression (suicidal attempt: Kate gets drunk alone in room and overdoses on pills)	
Psychopathology: Discussed with patient	<input type="checkbox"/>
Psychopathology: Discussed with family	<input type="checkbox"/>
Psychopathology: Discussed with treatment team	<input type="checkbox"/>
Psychiatric treatments: If yes, list:	
Psychiatric treatments	<input type="checkbox"/>
Psychopathology general comments:	
Not viewed as real psychopathology, mom says it is just form of self-pity and won't tolerate it.	
Stress: Finances	<input type="checkbox"/>
Stress: School	<input checked="" type="checkbox"/>
Stress: Social	<input type="checkbox"/>
Stress: Religious	<input type="checkbox"/>
Stress: Living situation	<input type="checkbox"/>
Stress general comments	
No evidence of Kate going to school or receiving tutoring. Generally seems socially isolated except for interactions with family and brief period where she is with Tyler.	
Stress for Patient:	
Worry about family; Lack of normalcy; Physical pain/changes; Challenge to self-esteem; Loss of significant other to cancer; Coping with death	

Stress for Mother: Obsession with caring for Kate; Never giving up fight or allowing others to do so; Fear of losing child, anticipatory grief; Strain in marriage
Stress for Father: Fear of losing child, anticipatory grief; Maintaining rational, big-picture view of situation; Strain in marriage because of disagreement about treatment goals
Stress for Siblings: Anna: Pressure to save Kate's life; Entrusted by Kate to help her die; Physical/emotional pain/toll of medical procedures; "I'm important too", Parentification (cleaning up Kate's stool, taking care of drunk Kate); Jesse: Neglect; Social isolation; Not involved in medical care; No avenue for expressing his emotions
Stress for Extended family: Aunt Kelly works part time to help family; Disconnected family not on same page when it comes to understanding severity of illness and treatment goals
Themes Saved by love; Friends with other sick kids; Social isolation; No stone left unturned; Palliative care = quitting; Anticipatory/parental grief; Sibling neglect/isolation/parentification; Physical/emotional toll of illness challenges self-esteem; Parental discord; Risky behavior because you're sick; Cancer alienates you; Father with denial; Negative view of palliative care; Compassionate oncologist, nicer hospital environment; Family comes together to help child; Child helping parents cope; Emotional toll on family

Supporter name:	Supporter category:	Supporter title:	Presence	Involvement	Efficacy
Dr. Farquad	Professional Medical	Oncologist	0	1	1
Dr. Chance	Professional Medical	Oncologist	2	2	2
Nurses (1 mean, 1 nice)	Professional Medical	Nurse	1	1	0
Sara Fitzgerald	Internal Non-Professional	Mother	2	2	2
Taylor Ambrose	External Non-Professional	Significant other	2	2	2
Miss Swearingen	Professional Psychosocial	Palliative care/ hospice specialis	0	1	0
Aunt Kelly	Internal Non-Professional	Close Family	2	2	2
Jesse Fitzgerald	Internal Non-Professional	Sibling	2	2	2
Anna Fitzgerald	Internal Non-Professional	Sibling	2	2	2
Brian Fitzgerald	Internal Non-Professional	Father	2	2	2
Extended family	External Non-Professional	Extended Family	1	1	0

VIII. APPENDIX B

SOURCES OF PSYCHOSOCIAL STRESS BY MOVIE

	Psychosocial Stress	A Lion in the House	Oscar and the Lady in Pink	Ways to Live Forever	The Darkest Light	Declaration of War	Letters to God	Restless	A Civil Action	Katie's Wish	Desperate Measures	Stolen Summer
Children	Procedures	X			X	X					X	
	Physical Symptoms (pain, hair loss)	X	X	X	X		X			X	X	
	Fear/Anxiety about Outcomes	X	X								X	
	Social (isolation, loss of friends, bullying)	X	X	X	X	X	X	X		X	X	X
	Lifestyle Disruption	X	X	X	X	X	X	X		X	X	X
	I'm Different (self-esteem, preferential treatment)	X	X					X				X
	Emotional Distress	X	X	X	X		X	X		X	X	X
Worry about Parents/Family						X				X	X	
Parents	Loss of Control	X							X			
	Lifestyle Disruption	X		X	X	X	X		X	X		X
	Emotional Distress	X	X	X	X	X	X	X		X	X	X
	Discord with Partner	X			X	X						X
	Decision-Making (medical, protecting child, guilt)	X			X	X				X	X	X
	Maintaining Image of Strength	X				X					X	X
	Hospital Environment					X					X	
Siblings	Feeling Left Out (medical experience)	X		X	X							
	Neglect (emotional, physical)	X		X	X		X					
	Meeting Parent's Expectations				X		X					
	Lifestyle Disruption	X		X			X	X				
	Responsibility of Caring for Sick Sibling / Taking on Parent Role							X				
	Discord with Parents	X			X		X					
	Emotional Distress	X		X	X		X	X				
General	Financial	X			X	X	X	X	X			
	School	X		X	X	X		X		X		
	Living Situation	X	X		X	X			X			
	Religion	X					X					X
	Social Environment	X	X	X	X	X		X	X	X	X	X

	Psychosocial Stress	The Haunting in Connecticut	Sisterhood of Traveling Pants	The Basketball Diaries	Looking for an Echo	Johnny	The Ride	Erin Brokovich	My Sister's Keeper	A Walk to Remember	One Last Thing	C Me Dance
Children	Procedures											
	Physical Symptoms (pain, hair loss)	X		X		X	X		X		X	
	Fear/Anxiety about Outcomes											
	Social (isolation, loss of friends, bullying)	X	X	X	X	X	X	X	X	X		X
	Lifestyle Disruption	X	X	X	X	X	X	X	X	X		X
	I'm Different (self-esteem, preferential treatment)	X	X	X	X	X	X	X	X	X	X	
	Emotional Distress	X	X	X	X	X	X	X	X	X	X	X
Worry about Parents/Family								X	X			
Parents	Loss of Control							X				X
	Lifestyle Disruption	X			X			X	X		X	
	Emotional Distress	X			X			X	X	X	X	X
	Discord with Partner	X						X	X			
	Decision-Making (medical, protecting child, guilt)				X			X	X	X	X	
	Maintaining Image of Strength							X				
	Hospital Environment							X				
Siblings	Feeling Left Out (medical experience)								X			
	Neglect (emotional, physical)				X				X			
	Meeting Parent's Expectations								X			
	Lifestyle Disruption	X			X			X	X			
	Responsibility of Caring for Sick Sibling / Taking on Parent Role							X	X			
	Discord with Parents				X			X	X			
	Emotional Distress	X			X			X	X			
General	Financial	X			X			X				
	School				X	X		X	X			X
	Living Situation	X				X		X				
	Religion											X
	Social Environment	X	X		X		X	X	X	X		

	Psychosocial Stress	Snowmen	Julie Walking Home / The Healer	The Ultimate Gift	Camino	Little Brother / Hello Brother	Birdie and Bogie	Swimming Upstream
Children	Procedures		X		X	X	X	
	Physical Symptoms (pain, hair loss)	X			X	X	X	X
	Fear/Anxiety about Outcomes	X		X	X	X		X
	Social (isolation, loss of friends, bullying)	X		X	X	X		
	Lifestyle Disruption	X	X		X	X	X	X
	I'm Different (self-esteem, preferential treatment)	X			X	X	X	X
	Emotional Distress	X	X	X	X	X	X	X
Worry about Parents/Family			X	X	X			
Parents	Loss of Control		X		X			
	Lifestyle Disruption	X	X	X	X	X	X	
	Emotional Distress	X	X	X	X	X	X	X
	Discord with Partner		X		X			
	Decision-Making (medical, protecting child, guilt)	X			X	X	X	X
	Maintaining Image of Strength				X	X		
	Hospital Environment							
Siblings	Feeling Left Out (medical experience)		X			X		
	Neglect (emotional, physical)					X		
	Meeting Parent's Expectations					X		
	Lifestyle Disruption		X			X		X
	Responsibility of Caring for Sick Sibling / Taking on Parent Role					X		X
	Discord with Parents				X	X		X
	Emotional Distress		X		X	X		X
General	Financial	X		X		X		
	School	X			X	X		X
	Living Situation		X	X				
	Religion		X		X			
	Social Environment	X		X	X	X		

IX. APPENDIX C

PSYCHOSOCIAL SUPPORT CHARACTERS AND THEIR RATINGS BY MOVIE

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
The Basketball Diaries	Bobby	External Non-Professional	Jim	Friends	1	1	1
The Basketball Diaries	Bobby	External Non-Professional	Basketball team	Friends	1	1	0

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
The Ride	Danny O'Neil	External Non-Professional	Smokey	Coach	2	2	2
The Ride	Danny O'Neil	External Non-Professional	Ms. Stillwell	Extended Family	2	2	2
The Ride	Danny O'Neil	External Non-Professional	Mr. Stillwell	Extended Family	2	2	2
The Ride	Danny O'Neil	External Non-Professional	Mrs. Stillwell	Extended Family	2	2	2
The Ride	Danny O'Neil	External Non-Professional	Boys at ranch	Friends	2	1	1

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
A Civil Action	Families	External Non-Professional	Community (neighbors)	Community	1	1	1
A Civil Action	Families	External Non-Professional	Jan (personal injury lawyer)	Other	2	1	1

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
Desperate Measures	Matthew Conner	External Non-Professional	Nate Oliver	Friends	2	2	2
Desperate Measures	Matthew Conner	External Non-Professional	Police Department colleagues	Friends	1	1	1
Desperate Measures	Matthew Conner	Internal Non-Professional	Frank Conner	Father	2	2	2
Desperate Measures	Matthew Conner	Professional Medical	Dr. Hawkins	Oncologist	2	2	2
Desperate Measures	Matthew Conner	Professional Medical	Nurses (2)	Nurse	1	1	2

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
The Darkest Light	Matthew	External Non-Professional	Community priest	Clergy member	1	1	1
The Darkest Light	Matthew	External Non-Professional	Town friends	Friends	1	1	1
The Darkest Light	Matthew	Internal Non-Professional	Tom	Father	2	2	1
The Darkest Light	Matthew	Internal Non-Professional	Sue	Mother	2	2	1
The Darkest Light	Matthew	Internal Non-Professional	Catherine	Sibling	2	2	2

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
Looking for an Echo	Tina Pirelli	External Non-Professional	Vic (Vinnie's best friend)	Friends	1	1	1
Looking for an Echo	Tina Pirelli	Internal Non-Professional	Vinnie Pirelli	Father	2	2	2
Looking for an Echo	Tina Pirelli	Internal Non-Professional	Anthony	Sibling	2	2	2
Looking for an Echo	Tina Pirelli	Internal Non-Professional	Tommie	Sibling	1	1	2
Looking for an Echo	Tina Pirelli	Professional Medical	Joanne	Nurse	2	2	2
Looking for an Echo	Tina Pirelli	Professional Medical	Dr. Ludwig	Oncologist	2	1	2

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
Erin Brokovich	Annabelle Daniels	External Non-Professional	Erin Brokovich	Other	2	1	2
Erin Brokovich	Annabelle Daniels	Internal Non-Professional	Rita Daniels	Mother	2	2	2
Erin Brokovich	Annabelle Daniels	Internal Non-Professional	Ted Daniels	Father	2	2	2

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
Stolen Summer	Danny Jacobsen	External Non-Professional	Pete O'Malley	Friends	2	2	2
Stolen Summer	Danny Jacobsen	External Non-Professional	O'Malley family	Friends	1	1	1
Stolen Summer	Danny Jacobsen	External Non-Professional	Jewish community	Community	1	1	2
Stolen Summer	Danny Jacobsen	Internal Non-Professional	Rabbi Jacobsen	Father	2	2	2
Stolen Summer	Danny Jacobsen	Internal Non-Professional	Mother	Mother	2	2	1
Stolen Summer	Danny Jacobsen	Professional Medical	Female doctor	Oncologist	1	1	2

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
A Walk to Remember	Jamie Sullivan	External Non-Professional	Landon Carter	Significant other	2	2	2
A Walk to Remember	Jamie Sullivan	Internal Non-Professional	Reverend Sullivan	Father	2	2	2

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
Julie Walking Home / The Healer	Nicholas	External Non-Professional	Other cancer child and family	Friends	1	1	1
Julie Walking Home / The Healer	Nicholas	External Non-Professional	Community priest	Clergy member	1	1	1
Julie Walking Home / The Healer	Nicholas	External Non-Professional	Alexy (faith healer)/assistants	Other	2	2	2
Julie Walking Home / The Healer	Nicholas	Internal Non-Professional	Julie	Mother	2	2	2
Julie Walking Home / The Healer	Nicholas	Internal Non-Professional	Henry	Father	2	2	2
Julie Walking Home / The Healer	Nicholas	Internal Non-Professional	Nicole	Sibling	2	2	2
Julie Walking Home / The Healer	Nicholas	Internal Non-Professional	Maternal grandfather	Close Family	2	2	1
Julie Walking Home / The Healer	Nicholas	Internal Non-Professional	Paternal grandfather	Close Family	1	1	1
Julie Walking Home / The Healer	Nicholas	Professional Medical	Main doctor	Oncologist	1	1	1

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
Swimming Upstream	Morris Bird III	External Non-Professional	Julie Sutton	Significant other	2	2	2
Swimming Upstream	Morris Bird III	External Non-Professional	Teddy Benevides	Friends	2	2	2
Swimming Upstream	Morris Bird III	External Non-Professional	English teacher	Teacher	1	1	2
Swimming Upstream	Morris Bird III	Internal Non-Professional	Sandra Bird	Sibling	2	2	2
Swimming Upstream	Morris Bird III	Internal Non-Professional	Morris Bird II	Father	2	1	1
Swimming Upstream	Morris Bird III	Professional Medical	Dr. Henry Berkson	Oncologist	2	2	2

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
Birdie and Bogie	Birdie O'Conner	External Non-Professional	Amy (mother-figure)	Friends	2	2	2
Birdie and Bogie	Birdie O'Conner	Internal Non-Professional	Danny O'Conner	Father	2	2	2
Birdie and Bogie	Birdie O'Conner	Internal Non-Professional	Uncle Lester	Close Family	2	2	2
Birdie and Bogie	Birdie O'Conner	Professional Medical	Dr. Scott	Oncologist	2	1	1
Birdie and Bogie	Birdie O'Conner	Professional Medical	Nurse	Nurse	2	2	2

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
The Sisterhood of the Traveling Pants	Bailey Graffman	External Non-Professional	Tibby	Friends	2	2	2
The Sisterhood of the Traveling Pants	Bailey Graffman	External Non-Professional	Brian	Friends	1	1	2

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
One Last Thing	Dylan Jameison	External Non-Professional	Slap, Ricky	Friends	2	2	2
One Last Thing	Dylan Jameison	External Non-Professional	Jason O'Malley	Friends	1	1	2
One Last Thing	Dylan Jameison	External Non-Professional	Nikki	Friends	1	2	1
One Last Thing	Dylan Jameison	External Non-Professional	Man in store in NY	Other	0	1	1
One Last Thing	Dylan Jameison	Internal Non-Professional	Karen Jameison	Mother	2	2	2
One Last Thing	Dylan Jameison	Professional Medical	Dr. Emerson	Oncologist	1	2	2
One Last Thing	Dylan Jameison	Professional Psychosocial	United Givers Foundation	Other	1	1	0

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
Little Brother / Hello Brother	HanByul	External Non-Professional	Wook (cancer patient)	Friends	2	2	2
Little Brother / Hello Brother	HanByul	External Non-Professional	Wook's family	Friends	1	1	2
Little Brother / Hello Brother	Wook	External Non-Professional	HanByul	Friends	2	2	2
Little Brother / Hello Brother	Wook	External Non-Professional	Hani	Friends	2	2	2
Little Brother / Hello Brother	Wook	External Non-Professional	HanByul's family	Friends	1	1	2
Little Brother / Hello Brother	Wook	External Non-Professional	Little Boy Jade (comedian)	Other	1	1	2
Little Brother / Hello Brother	HanByul	Internal Non-Professional	Mother	Mother	2	2	2
Little Brother / Hello Brother	HanByul	Internal Non-Professional	Father	Father	2	2	2
Little Brother / Hello Brother	HanByul	Internal Non-Professional	Hani	Sibling	2	2	2
Little Brother / Hello Brother	Wook	Internal Non-Professional	Mother	Mother	2	2	2
Little Brother / Hello Brother	Wook	Internal Non-Professional	Father	Father	2	2	2
Little Brother / Hello Brother	Wook	Internal Non-Professional	Grandmother	Close Family	2	2	2
Little Brother / Hello Brother	HanByul	Professional Medical	Dr. Na-Youngsoo	Oncologist	2	1	2
Little Brother / Hello Brother	HanByul	Professional Medical	Treatment team	Other	1	1	2
Little Brother / Hello Brother	Wook	Professional Medical	Dr. Na-Youngsoo	Oncologist	2	1	2
Little Brother / Hello Brother	Wook	Professional Medical	Treatment team	Other	1	1	2

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
A Lion in the House	Tim Woods	External Non-Professional	Beth Stevenson	Teacher	0	1	2
A Lion in the House	Tim Woods	External Non-Professional	Mr. Koon	Other	1	1	2
A Lion in the House	Alex Loughheed	External Non-Professional	Teacher	Teacher	0	1	1
A Lion in the House	Alex Loughheed	External Non-Professional	Classmates	Friends	0	1	1
A Lion in the House	Justin Ashcraft	External Non-Professional	Extended family	Extended Family	1	1	2
A Lion in the House	Justin Ashcraft	External Non-Professional	Community friends	Friends	1	1	2
A Lion in the House	Justin Ashcraft	External Non-Professional	Kathy (fundraising coordinator)	Other	0	1	1
A Lion in the House	Jen Moore	External Non-Professional	School-provided tutor	Teacher	0	1	1
A Lion in the House	Tim Woods	Internal Non-Professional	Marietha Woods	Mother	2	2	1
A Lion in the House	Alex Loughheed	Internal Non-Professional	Judy Loughheed	Mother	2	2	2
A Lion in the House	Alex Loughheed	Internal Non-Professional	Scott Loughheed	Father	2	2	1
A Lion in the House	Alex Loughheed	Internal Non-Professional	Jackie Loughheed	Sibling	1	1	1
A Lion in the House	Justin Ashcraft	Internal Non-Professional	Debbie Ashcraft	Mother	2	2	2
A Lion in the House	Justin Ashcraft	Internal Non-Professional	Dale Ashcraft	Father	2	2	2
A Lion in the House	Justin Ashcraft	Internal Non-Professional	Siblings (Adam)	Sibling	2	2	2
A Lion in the House	Justin Ashcraft	Internal Non-Professional	Grandmother	Close Family	1	2	2
A Lion in the House	Jen Moore	Internal Non-Professional	Beth Moore	Mother	2	2	2
A Lion in the House	Jen Moore	Internal Non-Professional	Frank Moore	Father	2	2	2
A Lion in the House	Al Fields	Internal Non-Professional	Regina Fields	Mother	2	2	2
A Lion in the House	Tim Woods	Professional Medical	Connie Koon	Nurse	2	2	2
A Lion in the House	Tim Woods	Professional Medical	Dr. Venod Balasa	Oncologist	2	2	2
A Lion in the House	Tim Woods	Professional Medical	Dr. Robert Arceci	Oncologist	1	1	2
A Lion in the House	Tim Woods	Professional Medical	Dr. Fred Huang	Oncologist	1	1	2
A Lion in the House	Alex Loughheed	Professional Medical	Dr. Paul Jubinsky	Oncologist	2	2	2
A Lion in the House	Alex Loughheed	Professional Medical	Dr. Robert Arceci	Oncologist	1	1	2
A Lion in the House	Alex Loughheed	Professional Medical	Home nurse	Nurse	1	1	1
A Lion in the House	Justin Ashcraft	Professional Medical	Dr. Claire Maseveski	Oncologist	2	2	2
A Lion in the House	Justin Ashcraft	Professional Medical	Treatment team	Oncologist	2	2	2
A Lion in the House	Justin Ashcraft	Professional Medical	Linda Polman	Nurse	1	1	1
A Lion in the House	Jen Moore	Professional Medical	Dr. DeLaat	Oncologist	1	1	2
A Lion in the House	Al Fields	Professional Medical	Lisa Crosby	Nurse	2	2	2
A Lion in the House	Al Fields	Professional Medical	Dr. Fred Huang (fellow)	Oncologist	1	1	2
A Lion in the House	Al Fields	Professional Medical	Dr. Scott (peds resident)	Other	1	1	1
A Lion in the House	Tim Woods	Professional Psychosocial	Barbara Heidt	Mental health nurse	0	1	2
A Lion in the House	Tim Woods	Professional Psychosocial	Dr. Robert Noll	Psychologist	0	1	1
A Lion in the House	Tim Woods	Professional Psychosocial	Chaplain	Hospital chaplain	0	1	1
A Lion in the House	Alex Loughheed	Professional Psychosocial	Dr. Robert Noll	Psychologist	0	1	1
A Lion in the House	Alex Loughheed	Professional Psychosocial	Hospice nurse	Palliative care/ hospice specialist	0	1	1
A Lion in the House	Justin Ashcraft	Professional Psychosocial	Dr. Zwerdling	Palliative care/ hospice specialist	2	2	2
A Lion in the House	Justin Ashcraft	Professional Psychosocial	Hospital chaplain	Hospital chaplain	1	1	2

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
The Ultimate Gift	Emily Rose	External Non-Professional	Jason	Friends	2	2	2
The Ultimate Gift	Emily Rose	Internal Non-Professional	Alexia	Mother	2	2	2
The Ultimate Gift	Emily Rose	Professional Medical	Oncologist	Oncologist	1	1	1
The Ultimate Gift	Emily Rose	Professional Medical	Nurse	Nurse	1	2	2

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
Katie's Wish	Katie Martin	External Non-Professional	Jennifer (Michael's girlfriend)	Friends	2	2	2
Katie's Wish	Katie Martin	External Non-Professional	Libby	Friends	0	1	1
Katie's Wish	Katie Martin	Internal Non-Professional	Michael Martin	Father	2	2	2
Katie's Wish	Katie Martin	Internal Non-Professional	Ed/Marge (grandfather/gr)	Close Family	2	2	2
Katie's Wish	Katie Martin	Internal Non-Professional	Karen (aunt)	Close Family	1	1	2
Katie's Wish	Katie Martin	Professional Medical	Steve	Primary Care Physician	1	1	2

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
Camino	Camino	External Non-Professional	Begona	Friends	2	2	2
Camino	Camino	External Non-Professional	Jesus	Significant other	1	1	2
Camino	Camino	External Non-Professional	Teacher	Teacher	0	1	1
Camino	Camino	External Non-Professional	Rafael	Extended Family	0	1	1
Camino	Camino	External Non-Professional	Priest	Clergy member	1	1	1
Camino	Camino	Internal Non-Professional	Gloria	Mother	2	2	1
Camino	Camino	Internal Non-Professional	Jose	Father	2	2	2
Camino	Camino	Internal Non-Professional	Nuria (Yeye)	Sibling	1	1	1
Camino	Camino	Internal Non-Professional	Tia Marita	Close Family	1	1	0
Camino	Camino	Professional Medical	Main doctor (neurosurgeon?)	Specialist	2	1	0
Camino	Camino	Professional Medical	ED Doctor	Specialist	1	0	0
Camino	Camino	Professional Medical	Navarro doctor	Oncologist	1	1	0
Camino	Camino	Professional Medical	Navarro doctor 2	Oncologist	1	1	0
Camino	Camino	Professional Medical	Nurse 1	Nurse	1	2	2
Camino	Camino	Professional Medical	Nurse 2	Nurse	1	1	2
Camino	Camino	Professional Medical	Nurse 3	Nurse	1	1	2
Camino	Camino	Professional Psychosocial	Hospital Chaplain - older	Hospital chaplain	2	2	1
Camino	Camino	Professional Psychosocial	Hospital Chaplain - younger	Hospital chaplain	2	2	1

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
Oscar and the Lady in Pink	Oscar	External Non-Professional	Rose	Friends	2	2	2
Oscar and the Lady in Pink	Oscar	External Non-Professional	Peggy Blue	Significant other	1	1	1
Oscar and the Lady in Pink	Oscar	External Non-Professional	Hospital friends	Friends	1	1	1
Oscar and the Lady in Pink	Oscar	External Non-Professional	Professor at institution	Teacher	1	1	2
Oscar and the Lady in Pink	Oscar	Internal Non-Professional	Oscar's mother	Mother	1	1	1
Oscar and the Lady in Pink	Oscar	Internal Non-Professional	Oscar's father	Father	1	1	1
Oscar and the Lady in Pink	Oscar	Professional Medical	Dr. Dusseldorf	Oncologist	2	2	2
Oscar and the Lady in Pink	Oscar	Professional Medical	Nurse	Nurse	2	1	1

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
The Haunting in Connecticut	Matthew Campbell	External Non-Professional	Reverend Popescu	Clergy member	1	2	1
The Haunting in Connecticut	Matthew Campbell	Internal Non-Professional	Sara Campbell	Mother	2	2	2
The Haunting in Connecticut	Matthew Campbell	Internal Non-Professional	Peter Campbell	Father	2	1	1
The Haunting in Connecticut	Matthew Campbell	Internal Non-Professional	Billy	Sibling	2	1	1
The Haunting in Connecticut	Matthew Campbell	Internal Non-Professional	Mary (young cousin)	Close Family	2	1	1
The Haunting in Connecticut	Matthew Campbell	Internal Non-Professional	Wendy (older cousin)	Close Family	2	2	2
The Haunting in Connecticut	Matthew Campbell	Professional Medical	Dr. Brooks	Oncologist	1	1	0

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
My Sister's Keeper	Kate Fitzgerald	External Non-Professional	Extended family	Extended Family	1	1	0
My Sister's Keeper	Kate Fitzgerald	External Non-Professional	Taylor Ambrose	Significant other	2	2	2
My Sister's Keeper	Kate Fitzgerald	Internal Non-Professional	Sara Fitzgerald	Mother	2	2	2
My Sister's Keeper	Kate Fitzgerald	Internal Non-Professional	Brian Fitzgerald	Father	2	2	2
My Sister's Keeper	Kate Fitzgerald	Internal Non-Professional	Anna Fitzgerald	Sibling	2	2	2
My Sister's Keeper	Kate Fitzgerald	Internal Non-Professional	Jesse Fitzgerald	Sibling	2	2	2
My Sister's Keeper	Kate Fitzgerald	Internal Non-Professional	Aunt Kelly	Close Family	2	2	2
My Sister's Keeper	Kate Fitzgerald	Professional Medical	Dr. Farquad	Oncologist	0	1	1
My Sister's Keeper	Kate Fitzgerald	Professional Medical	Dr. Chance	Oncologist	2	2	2
My Sister's Keeper	Kate Fitzgerald	Professional Medical	Nurses (1 mean, 1 nice)	Nurse	1	1	0
My Sister's Keeper	Kate Fitzgerald	Professional Psychosocial	Miss Swearingen	Palliative care/ hospice specialist	0	1	0

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
C Me Dance	Sheri	External Non-Professional	Ally, Claire	Friends	2	2	1
C Me Dance	Sheri	External Non-Professional	Pastor Jeff	Clergy member	1	1	1
C Me Dance	Sheri	Internal Non-Professional	Vince	Father	2	2	2
C Me Dance	Sheri	Professional Medical	Dr. Crowl	Oncologist	2	2	1

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
Ways to Live Forever	Sam	External Non-Professional	Felix	Friends	2	2	2
Ways to Live Forever	Sam	External Non-Professional	Ms. Willis	Teacher	2	2	2
Ways to Live Forever	Sam	External Non-Professional	Kaleigh	Significant other	1	1	2
Ways to Live Forever	Felix	External Non-Professional	Ms. Willis	Teacher	2	2	2
Ways to Live Forever	Felix	External Non-Professional	Sam	Friends	2	2	2
Ways to Live Forever	Sam	Internal Non-Professional	Daniel	Father	2	2	1
Ways to Live Forever	Sam	Internal Non-Professional	Amanda	Mother	2	2	1
Ways to Live Forever	Sam	Internal Non-Professional	Gran	Close Family	1	1	2
Ways to Live Forever	Sam	Internal Non-Professional	Ella	Sibling	2	1	1
Ways to Live Forever	Felix	Internal Non-Professional	Mother	Mother	1	2	1
Ways to Live Forever	Felix	Internal Non-Professional	Father	Father	1	2	1
Ways to Live Forever	Sam	Professional Medical	Annie (VNA)	Nurse	2	2	2
Ways to Live Forever	Sam	Professional Medical	Oncologist	Oncologist	1	1	1

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
Letters to God	Tyler Doherty	External Non-Professional	Sam	Friends	2	2	2
Letters to God	Tyler Doherty	External Non-Professional	Brady McDaniels	Friends	2	2	2
Letters to God	Tyler Doherty	External Non-Professional	Miss Emily	Teacher	1	1	2
Letters to God	Tyler Doherty	External Non-Professional	Mr. Perryfield	Friends	1	1	2
Letters to God	Tyler Doherty	External Non-Professional	Community (neighbors, priest)	Community	1	1	2
Letters to God	Tyler Doherty	External Non-Professional	Soccer coach	Coach	1	1	2
Letters to God	Tyler Doherty	Internal Non-Professional	Maddy Doherty	Mother	2	2	2
Letters to God	Tyler Doherty	Internal Non-Professional	Ben Doherty	Sibling	2	2	2
Letters to God	Tyler Doherty	Internal Non-Professional	Olivia (maternal grandmother)	Close Family	2	2	2
Letters to God	Tyler Doherty	Professional Medical	Nurses	Nurse	1	1	2
Letters to God	Tyler Doherty	Professional Medical	Oncologist (female doctor)	Oncologist	1	0	0

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
Johnny	Johnny	External Non-Professional	Kayla Carter (adoptive sister)	Friends	2	2	2
Johnny	Johnny	External Non-Professional	Mrs. Carter (adoptive mother)	Other	2	1	1
Johnny	Johnny	External Non-Professional	Little Willie	Friends	1	1	2
Johnny	Johnny	Professional Medical	Dr. Miller	Primary Care Physician	2	2	2
Johnny	Johnny	Professional Medical	Dr. Carter	Oncologist	2	2	2
Johnny	Johnny	Professional Medical	Dolores (Receptionist)	Other	1	1	2
Johnny	Johnny	Professional Psychosocial	Clyde (Counselor)	Other	2	2	2
Johnny	Johnny	Professional Psychosocial	Glenda	Social worker	2	1	2

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
Snowmen	Billy Kirkfield	External Non-Professional	Lucas, Howard	Friends	2	2	2
Snowmen	Billy Kirkfield	External Non-Professional	Principal Wetzel	Teacher	1	1	2
Snowmen	Billy Kirkfield	External Non-Professional	Community	Community	2	1	1
Snowmen	Billy Kirkfield	Internal Non-Professional	Mother	Mother	2	2	1
Snowmen	Billy Kirkfield	Internal Non-Professional	Reggie Kirkfield	Father	2	2	1

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
Declaration of War	Adam	External Non-Professional	Nikos (father's friend)	Friends	1	1	2
Declaration of War	Adam	Internal Non-Professional	Juliette	Mother	2	2	2
Declaration of War	Adam	Internal Non-Professional	Romeo	Father	2	2	2
Declaration of War	Adam	Internal Non-Professional	Grandparents	Close Family	2	2	2
Declaration of War	Adam	Professional Medical	Dr. Sainte-Rose (neurosurgeon)	Specialist	2	2	2
Declaration of War	Adam	Professional Medical	Dr. Fitoussi (neurologist)	Specialist	1	1	1
Declaration of War	Adam	Professional Medical	Dr. Prat	Primary Care Physician	1	1	1
Declaration of War	Adam	Professional Psychosocial	Social worker	Social worker	0	1	2

Movie Name	Patient Name	Supporter category:	Supporter name:	Supporter title:	Presence	Involvement	Efficacy
Restless	Annabel Cotton	External Non-Professional	Enoch	Significant other	2	2	2
Restless	Annabel Cotton	External Non-Professional	Hospital security guard	Other	1	1	2
Restless	Annabel Cotton	Internal Non-Professional	Elizabeth	Sibling	2	2	2
Restless	Annabel Cotton	Internal Non-Professional	Rachel	Mother	1	1	1
Restless	Annabel Cotton	Professional Medical	Dr. Lee	Oncologist	1	2	2
Restless	Annabel Cotton	Professional Medical	Nurses	Nurse	1	1	2

Themes	Subthemes	The Ultimate Gift	Camino	Little Brother / Hello Brother	Birdie and Bogie	Swimming Upstream
Disruption	Threat to a normal childhood		X	X	X	X
	Change in living situation	X	X	X		
Social Impact	Isolation and alienation	X	X			
	Families struggle alone			X		X
Psychological Impact	Preoccupation with death	X	X		X	X
	Find meaning in life / mature	X	X			X
	Emotional distress	X	X	X		X
Physical Toll	Physical changes / suffering		X	X	X	X
	Threat to self-esteem		X			
Struggle/War/Fight	Parents fight till the end			X		
	Cancer care as a horror show		X	X		
	War against carcinogens					
Coping	Reliance on religion and faith		X		X	
	Parental coping	X	X	X	X	X
	Child coping	X	X		X	X
Barren Landscape	Empty hospital environment		X	X		X
	No treatment team, limited mental health providers	X				X