A STUDY OF DIRECT CARE STAFF FOR INDIVIUALS WITH INTELLECTUAL

DISABILITIES/MENTAL ILLNESS REGARDING GRIEF AND LOSS ISSUES

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A Study of Direct Care Staff for Individuals with Intellectual
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ABSTRACT

Social service agencies often ignore death and dying issues (DDI). Direct care staff (DCS) are left to fend for themselves when it comes to these issues. Training on DDI and GLI is scarce. Theories such as Symbolic Interactionism and Awareness Theory help explain DDI and GLI. The methods used in this study include qualitative interviewing. Ten DCS were interviewed in 2012 from a Fargo social service agency. They were asked questions about their belief in DDI and their work with clientele. Addressed were their belief about DDI effects them personally and their educational background. Results indicated there were positive perceptions of disabled persons regarding GLI and DDI. The DCS believed the disabled individual grieves adequately with staff and family assistance. The disabled persons with whom DCS worked with understood DDI and GLI. The staff at this agency were not trained for GLI or DDI until such an incident occurred.

ACKNOWLEDGEMENTS

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ACRONYMS

CID ....Crisis Incident Stress Debriefing Program

CRUSE ....Non-denominational Bereavement Care Organization

DCS ....Direct Care Staff

DDI ....Death and Dying Issues

GLI ....Grief and Loss Issues

ID ....Intellectual Disabilities

MHI ....Mental Health Issues

DSM ....Diagnostic Manual of Statistic Disorders

SHOULDER ....Supportive Help Offering Understanding to People Who Have a Learning Disability

CHAPTER ONE: INTRODUCTION

Background of Grief and Loss Issues in the Social Services

Death and dying issues (DDI), especially grief and loss issues (GLI), are often

ignored in routine services provided by social service agencies. There is often a lack of

training and education in the typical social service agency on DDI and GLI. These issues

are important because social workers, direct care staff (DCS), and other team members

must have knowledge of these pertinent issues in order to help people with intellectual

disabilities (ID) or mental health issues (MHI) (Davison & Foster, 2003; Silverman, 2003).

Thus, a social support network between staff members and other agencies is the key to

helping agency members as well as agency clientele (Olsson, 1997, p. 117). Finally, it is

important to recognize that training and education on GLI is driven by effective

communication between social service team members (Strickland & DeSpelder, 2003).

Grief is a "reaction to any kind of loss" (Goldsworthy, 2005, p. 176), which

everyone faces at some point in their lives (Deutsch, 1985). People have grief reactions

because they "believe that (they)… have lost something valuable" (Attig, 2004, p. 343).

The reaction may be postponed or instantaneous and grief may occur as numerous

"physical, behavioral, and spiritual responses" (DeSpelder & Strickland, 2005, p. 268).

Also, grief is healthy and normal (Hoover, Markell, & Wagner, 2004-05), evolves over

time and may encourage personal and emotional growth (Klenow, 2007, personal

communication).

Individuals with ID/MHI often confront disenfranchised grief. The individual with

an ID may experience a more difficult adjustment due to this type of grief. Disenfranchised

grief is grief which is marked by a lack of social recognition and social support (Doka, 2002). When this grief from a loss is left unrecognized, it may cause a psychiatric condition or enhance preexisting psychiatric conditions. This can severely impact both the individuals and DCS.

Losses may be subtle, lack clarity, be continuous, and be evolving (Goldsworthy, 2005). DDI are important problems to consider when dealing with individuals who have ID/MHI because they view loss differently from others. These individuals often face multiple losses. For example, they may face a loss of self-worth from the "responses of a non-disabled society towards them" (Sapey, 1996, p. 147). Thus, people in the mainstream population may treat them differently than others in society. This type of loss devalues the individual who has ID/MHI.

There are many other losses that these individuals encounter. The death of a primary caregiver such as a parent is one of these losses. If the individual lived with their primary caregiver, he or she often faces relocation after the death of their parent, which may result in serious psychiatric complications (McHale & Carey, 2002). Other family members may not be able to effectively fill the void left by the parent. As a result, the surviving family members may withdraw from their relationship with the person with ID/MHI or vice versa (Kauffman, 1994, 2005). Finally, there are additional losses that these individuals must confront as a result of residential placement and daily interaction with DCS. They may lose their personal freedom such as moving from an apartment to a group home or another institutional facility; they may change workplaces; they may lose DCS; or their roommate may move away. The individual with ID/MHI may never be able

to see these persons again and they experience a loss of friendship (Runnion & Wolfer, 2004).

DCS members are social service staff who work with the individuals with ID/MHI in their homes on a weekly or daily basis. Staff members are often the sole source of social support and friendship for the individual. They are a "primary source of nurturance of the human bond" and the "*human context* in which other support tasks are carried out" (Kauffman, 2005, p. 99). However, staff members may not always be aware of primary or other familial losses and other life events of the individuals who they serve (Hastings, Hatton, Taylor, & Maddison, 2004; Stoddart, Burke & Temple, 2002).

Staff members may face personal loss due to the death of the individual who has ID/MHI when they receive another placement in the agency or when they leave the agency (Fauri & Grimes, 1994). Personal losses by staff members at work may inhibit their ability to perform as a staff member and their ability to cope with losses in their private lives (Cathcart, 1995; Kauffman, 1993, 2005). Staff may leave the agency due to burnout, inadequate pay, or the inability to confront the serious psychiatric and/or physical conditions that these special populations face on a daily basis (Runnion & Wolfer, 2004). When team members leave their position with the individual or when they leave the agency, it is often done abruptly and without saying goodbye. Vulnerable individuals at social service agencies frequently confront a continual form of loss because of these staffing issues (Kauffman, 1993, 2005; Runnion & Wolfer, 2004).

Given this information about loss, it is important to understand the intricacies of ID/MHI. The medical model of disability indicates that ID is "impairment within the individual mind or body" and the sociological model indicates that it causes "restrictions

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due to social responses to unusual bodies and the environment" (Dingel, personal communication, 2008). The medical model views ID as "talk of symptoms, diagnosis and disorder," whereas the sociological model defines it as a "hypothetical construct of recent coinage in its current form, and as with its historical predecessors, pervasively attentive to matters of moral conduct" (Rapley, 2004, p. 76).

Mental illness is not just a psychiatric condition, but also a social condition. The medical model "views mental illness as an objective reality (if subjectively experienced)" (Weitz, 2007, p. 190) and as with ID, the sociological model views mental illness as a "social construction based on social judgments of some condition in the world" (Conrad & Schneider, 1980, p. 36). Using the sociological viewpoint, mental illnesses are the "products of the society in which they exist" (Conrad & Schneider, 1980, p. 20). Mental health professionals in particular exert a high level of social control and discretion over the mentally ill in society (Horwitz, 1982).

The medical model of disability views disability as a psychiatric or mental state, whereas the sociological model of disability views disability as a deviant social or moral condition. For example, a medical doctor may diagnosis a person with a mental disability such as schizophrenia. This medical diagnosis is based on very specific criteria medical professionals have agreed upon using the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* series. However, the societal view of schizophrenia is not based on medical criteria. A person with schizophrenia, or a mental illness, often displays behavior which deviates from normal societal expectations. This behavior is labeled as deviant and thus, the person is mentally ill by societal standards, not by prescribed medical standards.

Individuals with ID may exhibit special characteristics such as "obsessive tendencies, concreteness of thought and strong dependency needs" (Kauffman, 1994, p. 260). The individuals may often express themselves through their non-verbal behavior because they are not able to effectively express themselves verbally (e.g., Kauffman, 1994, 2005; Stoddart et. al., 2002; Runnion & Wolfer, 2004). They may also display a wide range of "challenging behaviours" (Murray, McKenzie & Quigley, 2000, p. 79) which may deteriorate even further when facing loss and grief. The public already has "low expectations" (Read, 2005, p. 33) of individuals with ID/MHI and they may stereotype or stigmatize the individual as a result.

When dealing with DDI and other life events, it is not appropriate to treat adults with ID as children. The extent of how much these individuals comprehend death and dying experiences depends on their ID level, not their chronological age. The ID level may be profound, severe, moderate, or mild. Comprehension also depends upon their estimated intellectual age for each ID level (Bihm & Elliot, 1982; Van de Kerhof, 2006). Finally, it is important to note that "IQ is not consistently or significantly correlated with the development of […the death] concept" (Lipe-Goodson & Goebel, 1983, p. 73) in people with ID.

A final characteristic of ID deals with the individual's socio-emotional level, which is a secondary factor to intelligence level. People with ID generally have lower socioemotional developmental levels. The individual with an ID/MHI is often not in a position to choose their source of social support or they may even not recognize that they need help in the first place. The individual must rely on DCS and family members to recognize the need for support and the family and/or staff must provide the avenue for this

support (e. g., Kauffman, 1994, 2005; Kloeppel & Hollins, 1989; Runnion & Wolfer, 2004).

During revisions of the first and second version of the *DSM*, many mental health professionals disagreed over a definition of mental illness and even the definitions of specific subsets of mental illness (e. g., Kirk & Kutchins, 1992; Spitzer, Williams, & Skodal, 1980). However, professionals agreed upon a definition for mental disorder in the third version of the *DSM*. The *DSM-III* defines a mental disorder:

> As a clinically significant behavioral or psychologic syndrome or pattern that occurs in an individual and that is typically associated with either a painful symptom (distress) or impairment in one or more important areas of functioning (disability). In addition there is an inference that there is a behavioral, psychologic or biologic dysfunction and that the disturbance is not only in the relationship between the individual and society. When the disturbance is limited to a conflict between an individual and society, this may represent social deviance, which may or may not be commendable, but is not by itself a mental disorder (Spitzer et al., 1982, p. 153).

The *DSM-IV* does not give a competing definition of mental disorder (American Psychological Association, 2000).

One major factor that contributed to mental health professionals' inability to initially collectively define mental illness in the *DSM* was that they could not agree upon the origin of mental illness. Some professionals contended that mental illness was a case of nature versus nurture or sometimes a mixture of both cases. In other words, some mental health professionals viewed mental illness as a social rather than a medical category. As a result, MHI are difficult to diagnosis and the diagnoses often suffer from variations in diagnostic reliability (e.g., Kirk & Kutchins, 1992; Mirowsky & Ross, 1989; Spitzer et al., 1980).

Problem Statement

Larger structural issues take precedence over GLI of clientele in social service agencies. A significant amount of literature exists that indicates that unaddressed GLI may lead to greater emotional problems for the individual with ID/MHI. However, little research has been done on the DCS and how they handle DDI and GLI when they arise for the individuals and themselves.

The purpose of this study is to examine GLI and DDI and how they relate to the self-observations of DCS when working with their clientele. I will accomplish this purpose with the following two objectives. The first objective is to establish what the relationship is between DCS and clientele. For example, are they just staff and clientele or supervisor and clientele? The second objective is to discover what role knowledge and training play in the overall social services picture.

Research questions include the following. First, what general knowledge do DCS members have of GLI? Do DCS accurately gauge the individuals with ID/MHI and their ability to deal with the consequences of death and dying situations? Second, are social service agencies attempting to address DDI with staff through training and education programs? Are staff adequately trained to recognize the psychiatric signs and symptoms of grief from loss? Do agencies routinely include training and education on grief and loss issues for DCS? Finally, what personal attitudes do DCS have about DDI and how does this influence their ability to handle GLI when presented with these issues on the job?

Lack of Attention to Grief and Loss Issues in Social Service Agencies

GLI are relatively new topics of serious interest in social work (Kramer, 1998; Kramer, Pacourek, & Hovland-Scafe, 2003; Todd, 2002). There are several reasons for lack of attention to these phenomena, including America's unwillingness to openly deal with DDI, the devaluation of individuals with ID/MIH, stereotyping individuals into a one size fits all category, and structural constraints of the social services. Furthermore, along with death, intellectual disabilities are among "two of the most powerfully denied elements of our culture" (Emerson, 1977, p. 46).

First, the US is a death denying society. This denial is pervasive and plays itself out in all facets of life (e.g., Corr, 2003; Emerson, 1977; Ross, 1981; Todd, 2002). Some examples of these facets include multimedia, the medical profession, the place of death, and religious beliefs. Multimedia such as the mass media, music, literature, and films demonstrates this trend by dramatizing or inaccurately portraying death. Television often portrays death as nonexistent through cartoons and miraculous recoveries of program characters. Music and poetry may romanticize death and give it human characteristics.

The medical profession serves as another form of the denial of death in American society. According to one death sociologist, "hospitals are organized to hide the facts of dying and death from patients as well as from visitors" (Blauner, 1976, p. 43). The physical structure of the hospital, such as morgue placement and movement of patients near death, allow death to be hidden from the general public (Blauner, 1976). Healthcare professionals become skilled in the art form of deceit as they finesse information to conceal the real condition and prognosis of the patient. Hope is routinely kept alive even though it may not be practical (Glaser & Strauss, 1965; 1976).

Second, people with ID/MHI are often devalued in society. They are often not seen as capable people with genuine emotions and experiences. A popular conception is that death is not an understandable or tangible concept for those with ID (e.g., Kauffman, 1994, 2005; Ross, 1981; Runnion & Wolfer, 2004). However, many studies of these individuals show that they generally are aware of the death and dying process. Most are not afraid or distressed to talk about the issues (Gilrane-McGarry & Taggart, 2007).

Third, these individuals are often stereotyped as a single group rather than a group of individuals with personal wants and needs. They are sometimes seen as unable to handle or process the emotions associated with DDI. Individuals with ID/MHI are frequently kept from the truth about a death of a relative or a friend. Studies indicate that this secrecy practice is not only unethical, but detrimental to the individual. In fact, an individual sheltered from the death and dying process has more emotional harm done than good and reinforces societal stereotypes (e. g., Kauffmann, 1994, 2005; Read, 2005; Todd, 2002).

Finally, routine social services take precedence over these important issues because social service agencies fail to realize that grief and loss severely impact individuals with ID/MHI in all facets of their life. Social service agencies are often over tasked with essential services for the individuals that they serve. Also, limited budgets and time constraints are pervasive. Agencies often deal with DDI on an ad hoc basis instead of pre-planning responses for each individual (Runnion & Wolfer, 2004).

Rationale for the Study

Addressing GLI is a universal human need, important to mental health as well as physical health. Literature consistently indicates that unaddressed GHI for individuals with ID/MHI result in complications which may involve increased behavioral and psychiatric problems. Consequently, they may present social or psychological difficulties for DCS within the agency. Studies indicate DCS who are incapable of dealing with these DDI and GLI are in turn detrimental to those individuals who they serve (e. g., Cathcart, 1994; Kauffman, 1994, 2005; Hastings & Remington, 1994). This study is important because staff knowledge and views are rarely addressed in the literature.

Summary

DDI are routinely pushed aside by social service agencies because of budget, time constraints, lack of knowledge, and the societal denial of death and dying in society (Cathcart, 1995; Todd, 2002; Blauner1976). The absence of education and training programs and appropriate counseling services or referrals are often to blame for these inconsistencies in staff awareness. As a result, DCS and the individuals that they serve generally suffer the emotional consequences and lack of expertise in dealing with GLI.

CHAPTER TWO: LITERATURE REVIEW

Impact of Death and Dying Issues on Mental Health

Social work's renewed interest in DDI has created awareness that DDI may cause special psychiatric issues for the individual. These issues may bring on a previously nonexistent mental illness such as depression, intense grief, or anxiety (e. g. Dodd, Dowling, & Hollins, 2005; Kauffman, 1994, 2005; Kloeppel & Hollins, 1989). The individual with a preexisting psychiatric MHI is particularly vulnerable to the social stress of death. Without support and guidance, DDI will likely compound the individual's existing psychiatric issues (Macias et al., 2004). These individuals often need family or staff to offer guidance and support and may need professional grief counseling (e.g. Cathcart, 1995; Kauffman, 1994, 2005; Read, 2005).

Counseling Services on Death and Dying Issues

Because of these special psychiatric issues, individuals with ID/MHI must have appropriate grief counseling services based on the individual's intellectual age, but not based solely on the individual's chronological age when confronted with DDI (e.g. Bihm & Elliot, 1982 Kaufmann, 1994, 2005; Rothenberg, 1978; Van de Kerhof, 2006). Counseling interventions including staff and family may help the individual adjust to DDI. However, these interventions must be decided on a case by case basis. The type of therapy that an individual receives is important. Group therapy may be helpful in certain situations as opposed to individual cognitive therapy. Researchers agree that therapy should be discontinued on a gradual basis instead of withdrawn all at once. In any case, counseling

interventions require careful monitoring by social workers and other professionals (e g., Arndt & Gruber, 1977; Blackman, 2002; Davison & Foster, 2003, 1995).

DCS and family members may be involved in the counseling process. This involvement is often therapeutic for the staff member and the family member. Also, the process may help members of the family explore their own feelings about death and dying issues and their own mortality. Staff members who are comfortable with their own mortality are often able to help the individuals that they serve process their emotions when confronting DDI (e.g., Botsford, 2002; Cathcart, 1995; Kauffman, 1994, 2005).

There have been counseling interventions that illustrate examples of individuals with ID/MHI and how they cope with death and dying issues. For example, Eleanore Rothenberg (1994) embarked on a case study of a 30 day bereavement intervention program for a small group of intellectually disabled individuals who faced the sudden death of a beloved peer. For the group therapy sessions, social workers and DCS coordinated individual levels of intervention efforts. They combined theories and principles of social work practice with knowledge about loss theory and theories of grief progression. Techniques included the life cycle approach and art therapy. Individual sessions focused on similar, but personal goals.

There were major successes in implementing the group process. Combining group and one on one sessions was effective. Social service team members maintained appropriate teaching techniques that helped the individuals effectively deal with the GLI. Voluntary participation by essential group members, such as direct care staff, was slow at first because group participant members were generally unfamiliar with social work group

theory. Gradually, this problem self-corrected as group members became more familiar and comfortable with the process.

<center>Social Service Training Programs and Educational Programs</center>

In addition to counseling services, there are many training methods and educational programs to proactively help those with ID deal with DCS, some of which involve the family. For example, decisions about care for the individual should be made by the social service team before the primary caregiver or guardian dies. These decisions are often uncomfortable to the family and rarely made in advance. Prior planning may head off potential grief complications for the individual. This is especially true for those individuals who live with their primary caregiver (Kauffman, 1994, 2005; McHale & Carey, 2002).

Educational activities may help the individual adjust to death and dying situations before they arise. These activities may include field trips to funeral homes, cemeteries, and churches which "should be augmented by guest presentations from morticians, physicians, and the clergy" (Yanok & Beifus, 1993, p. 146). It is important to engage in a form of drama therapy or role playing with individuals about proper conduct at surrounding death and dying rituals (Cathcart, 1995). Also, staff and family may utilize a "storytelling style in educational efforts to facilitate recall of information" (Kloeppel & Hollins, 1989, p. 36), which will help the individual grieve.

Specific programs also help caregivers teach individuals about DDI (Botsford, 2002; Cathcart, 1995). For example, "The Communicating About Loss & Mourning (CALM) Curriculum" (Yanok & Beifus, 1993, p. 145) teaches an individual with intellectual disabilities and mental illness proper behavior and conduct during death and

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dying situations. This four step *"response approach"* involves "(a) modeling behavior, (b) rehearsal, (c) feedback, and (d) practice in the natural environment" (Yanok & Beifus, 1993, p. 147).

Other programs include Supportive Help Offering Understanding to People who have a Learning Disability (SHOULDER) and CRUSE. SHOULDER, is a program that "was established to overcome the many organizational and practical challenges identified when working with this client group" (Gilgrane-McGarry and Taggert, 2007, p. 141). The intervention made "access to generic counseling services" (Gilgrane-McGarry and Taggert, 2007, p. 141) easily available to individuals. CRUSE is the dominant bereavement organization in the United Kingdom whose name "is derived from a passage in the Old Testament about a widow's cruse, or a jar of oil, which never ran out thus signifying that support will be given as long as it was needed" ("Cruse Bereavement Care", 2006, ¶ 1). It is a voluntary and non-denominational, agency which "help(s) prepare staff working with dying and bereaved people" (Cathcart, 1995, p. 172). The program is an effort to have collaborative training between staff members. A final model is a variation on the Critical Incident Stress Debriefing (CID) program for first responders. The program helps staff members who have an individual who they serve die. It also helps them work with individuals with ID/MHI who have family members or friends die (Cathcart, 1995).

DCS, the individuals who they serve, and their families should learn basic facts about DDI because knowledge helps relieve fear of the unknown. Thus, stress surrounding DDI may decrease by increasing one's knowledge (e.g., Davison & Foster, 1995; Kramer, et. al., 2003; Yanok & Beifus, 1993). For example, some programs utilize a "visual and

pictorial mode" (Mapping & Hanlon, 2005, p. 108). The program's nonverbal techniques are more suited towards individuals with ID (Botsford, 2002; Mappin & Hanlon, 2005).

One visual and pictorial program teaches adults with ID/MHI about DDI using the life cycle approach of animals. The life cycle approach "establish(es) the notion that living things exist within a time-scale (the life cycle) and …promote(s) and understanding of development with its associated changes" (Mappin & Hanlon, 2005, p. 107). Animals such as a bird and the butterfly represent the life cycle. Pictures symbolize each step in the life cycle. The instructor asks the individuals "to get in touch with their feelings about death, dying, and loss" (Hedger & Smith, 1993, p. 33). The final step involves teaching the individual about a human's life cycle (Hedger & Smith, 1993).

There are many other recommendations. When discussing DDI, staff should teach and utilize appropriate terminology with the individual. Staff should not verbalize "euphemisms such as passing on, kicking the bucket, and meeting one's maker" (Yanok and Beifus, 1993, p. 147). "Clear and concise language is required at all times" (Read, 2005). Next, individuals must be taught that the "knowledge that death is a universal, irreversible, and inevitable outcome of the natural aging process" (Yanok and Beifus, 1993, p. 146). Additionally, staff may respectfully "encourage emotional release and expression" (Read, 2005, p. 34) of feelings about a death and dying event. However, the staff should respect the individual's wishes if they do not want to share feelings. Finally, observing anniversaries and talking about the deceased individual are important tools for healthy grieving.

Researchers agree that "a variety of media including practical exercises, video, (and) flip chart work" (Mappin and Hanlon, 2005, p. 107-108) helps facilitate healthy grief

work for individuals. Art or drawing sessions for the individual may be a useful tool for staff (Botsford, 2002; Cathcart, 1995). Multimedia such as videos or drama therapy help verbalize emotions and feelings surrounding the event (Rothenberg, 1994). Additional tools include written material such as books or pamphlets on DDI which are specifically geared towards individuals with ID (Botsford, 2002; Cathcart, 1995; Elliot, 1983). Staff can help the person create life story books, memory books, or a family tree. An "eco17 map," or a "diagram of significant others" (Elliot, 1983, p. 28), may serve as a substitute for a family tree.

Mementos and rituals surrounding DDI may facilitate the healing process. Team members or family members could facilitate a discussion of feelings or emotions surrounding mementos such as jewelry, photographs, and clothing of the deceased. Finally, individuals with ID/MHI may benefit from participation in the funeral or memorial service. Visiting the deceased's grave site with other family members or staff members may prove to be therapeutic (e.g., Cathcart, 1995; Gilgrane-McGarry & Taggert, 2007; Kauffman, 1993, 2003).

Related Sociological Theory

I will use sociological theories of symbolic interactionism and awareness theory to explore the world of DDI/GLI. These theories will guide the researcher during this qualitative study. The theories will help analyze interviewees responses to questions posed by the researcher.

Symbolic Interactionism

  Symbolic Interactionism is a longstanding and evolving sociological theory, which

helps set the stage for understanding GLI and the person with ID/MHI. George Herbert

Mead, a predominant symbolic interactionist, may be utilized to understand those

individuals with ID who deal with GLI. Mead theorized that everyone possesses an "I,"

"me," and a "generalized other." The " 'I' is the response of the organized set attitudes of

others which one himself assumes. The attitudes of others constitutes the organized 'me'

and then reacts toward that as an 'I' " (Morris, 1962, p. 175). The I and the me interact to

form a social self and respond to social situations.

  According to Mead, the person develops their social self through the "play" and

later on through the "game," which is a type of social play or social interaction with other

people. Play is interaction with others while being aware of one's self. The person is self-

centered and being a team player is not a concern. In the game, such as in Mead's example

of the baseball team, all players have the same attitude or same common goal. For true

realization of the social self, rules learned from the game need to be applied to over a wide

range of social situations. The person learns to navigate through the social world and

develop a social self through their interaction with others (Morris, 1962). Although the

definition may vary, all symbolic interactionists focus on the social self. As a general

definition, the "self (is seen) as an object, (it is) social in origin, …(and it) undergoes

change through interaction" (LoConto & Berry, 2002, p. 39).

  Sociality is a concept related to the social self that can be applied to individuals

with ID and GLI. "Sociality is the capacity of being several things or having several

identities at once. Humans are constantly in a state in which they are acting out various

identities" (LoConto & Berry, 2002, p. 39). For example, a person can be a mother,

teacher, sister at the same time. Furthermore, "sociality is the key to adjustment during the

grieving process" (LoConto & Jones-Pruett, 2008, p. 27).

There are some important differences in the sociality of people in the general

population and individuals with ID. Everyone in the general public normally develops

hundreds of identities while people with ID do not develop as many. The general public is

often able to compensate and recover from grief more quickly because of these multiple

identities whereas people with ID may often find it difficult to move on (LoConto &

Arrington, 2007). According to symbolic interactionists, the lack of identities is the reason

why people with ID have more problems coping with GLI than the mainstream population.

When their problems from GLI are left unattended, the perspective explains why their

unspoken desperation for help turns to behavioral problems socially expressed through

anger (LoConto & Berry, 2002; LoConto & Jones- Pruett, 2008).

The theories of symbolic interactionist Erving Goffman may be utilized to

understand individuals with MHI dealing with GLI and their interactions with their direct

care staff. Goffman (1961) wrote about people with MHI and their interactions with their

direct care staff in *Asylums: Essays on The Social Situation of Mental Patients and Other

Inmates*. A key component to the mental hospitalization system is the relationship between

the patient and the staff member. Goffman (1961) reveals that staff function in

> *personal-service occupation* may be defined, ideally, as one whose practitioner
> performs specialized personal service for a set of individuals where the service
> requires him to engage in direct personal communication with each of them and
> where he is not otherwise bound to the person he serves. (p. 324)

The relationship is one of mutual respect in that the patient expects competent service from staff who possess various skill levels whereas staff expect cooperation from the patient.

Goffman (1959) theorized in *The Presentation of the Self in Everyday Life* that everyone has a front stage and a backstage persona as an actor in a theater setting. An actor may appear on stage as an actor and off stage as his true self. The audience is only allowed front stage without a backstage pass. A third group identified by Goffman (1959) is the *outsiders* who are not allowed front stage or back stage. However, they may at times interrupt the performance with the consequence of receiving a performance "which the performers or the audience would ordinarily present before the outsiders at a time and a place when the outsiders would be the anticipated audience" (Goffman, 1959, p. 135).

Teams also play an integral role in a functioning society. In the mental hospital example, a team of healthcare professionals works together to help the patient through the recovery process utilizing tools such as charting and personal communication skills. According to Goffman (1959), this process is "fostered and sustained by the intimate cooperation of more than one participant" (p. 77-78). The teams either work together well, giving similar impressions separately to the mental patient, or they end up projecting incongruent messages to the patient.

Goffman's theories are easily applied to the relationship between DCS and individuals with MHI. The staff person may put up a front to protect the individual from GLI while at the same time, their back stage persona may feel that they should tell the person about the GLI. In this case, the outsiders may be professionals from other agencies which may become involved if problems develop from the GLI. In order for staff to be successful in maintaining secrecy about GLI, they must work together as a cohesive unit.

There may be instances where staff do not agree and either tell the individual anyway or inadvertently give information away by nonverbal clues.

Awareness Theory

Barney Glaser and Anselm Strauss (1965) developed the awareness theory of dying in their book *Awareness of Dying*. Awareness theory indicates that dying occurs in four different awareness contexts which are open, mutual pretense, suspicion awareness, and closed. The awareness contexts focused on the types of interactions between the dying patient and his team of healthcare professionals. Glaser & Strauss (1976) indicate that some parts of the theories of interaction from other social theorists such as Mead and Goffman resemble these awareness contexts.

In open awareness, both the dying patient and the healthcare professionals are aware of the patient's impending death. Glaser & Strauss (1976) say that Mead's theories of interaction with others were based on an open awareness context because of his interest in "shared communication" (p.149) with others. In mutual pretense, both parties are aware but neither acknowledges this awareness to the other with full awareness of the other's knowledge. In the suspicion awareness context, the patient suspects that he is dying, but he is not sure whether or not it is true because the healthcare professional has neither confirmed nor denied it (Glaser & Strauss, 1965).

In the final awareness context or the closed context, the patient is not aware of the impending death, but healthcare professionals are aware of the impending death. Teamwork among staff is a key component in this context. The staff members must not let the person overhear conversations or give non-verbal clues that something is wrong. Some

staff may sabotage the efforts of the team by deliberately giving these clues that may lead

to other contexts (Glaser & Strauss, 1976).

Glaser & Strauss (1965; 1976) theorized that closed awareness may eventually

evolve into other awareness contexts without staff sabotage. The change from one

awareness context to the next may be done "smoothly and easily, or explosively and

brutally, into another awareness context, depending on how the closed awareness was

managed" (Glaser & Strauss, 1965, p. 46) and how the deceit was discovered. Thus,

change in awareness contexts may have harmful and unintended negative consequences

unforeseen by staff members. The evolving context negates the original positive effects

intended by trying to maintain the closed awareness context.

Glaser & Straus (1976) found applications of the awareness contexts in Goffman's

theories of social interaction. According to Glaser & Strauss (1976), Goffman's main

concern was "on how the interaction …(was) kept going, or if disrupted, how interactants

manage to get it going again" (Glaser & Strauss, 1976, p. 151). More specifically,

Goffman's work primarily focuses on the mutual pretense and the closed awareness

contexts (Glaser & Strauss, 1976). For closed awareness, teamwork serves the purpose of

hiding facts from patients in the mental hospital in a carefully choreographed performance

for the mental patient (Goffman, 1959). For mutual pretense, the dying patient and hospital

workers maintain a sense of safety in conversation without explicitly addressing death and

dying issues (Glaser & Strauss, 1976).

When applying awareness contexts to direct care staff and the individuals that they

serve, the connection becomes clear. Staff members may be forced to keep a closed

awareness context due to the social service agency policy or the individual's guardian or

family wishes. Thus, they may not be allowed to share news of DDI about loved ones whether or not they agree with the decision.

In a social service agency, the forced closed awareness may have several negative consequences. First, in accordance with Glaser's awareness theory, the awareness context may inadvertently evolve into full awareness. If the individual finds out that information was withheld intentionally they may not trust that staff member as much as they did before. Second, the staff member may disregard the wishes of the agency, guardian or family and tell the person about the DDI anyway. Finally, the staff member may comply with the wishes of the agency, guardian and the family and the staff member may be become uncomfortable with their interaction with the individual.

Sociology of Death

The sociology of death encompasses a wide range of phenomena and it is best described as a socio-cultural phenomenon with an interconnected psychological component (Bendiksen, 1976; Blauner, 1976). Cultural and religious aspects play a central role in death because every culture has its own unique responses to DDI (Rothaupt & Becker, 2007). Culture plays an integral role in any human society. Ethnic groups within cultures often follow the same traditions but, diversity within the groups allows for individualism and behavior that is not predictable. Therefore, an individual can expect that death and dying will not be seen in the same light by all members of a particular ethnic group (Cowles, 1996; Rothauput & Becker, 2007).

Death and religion have sociological strong ties. Some theorize that religion may have developed as a response to DDI (Bendiksen, 1976). Religious beliefs often affect how

an individual views DDI and how members of society stay connected with the deceased individual (Rothaupt & Becker, 2007). Current studies show that Americans who attend church services on a regular bias have a tendency to believe in the afterlife (Klenow & Bolin, 1989).

Religious beliefs often "provide meaning for life and death" (Ross, 1984, p. 8) for the individual. In the medical arena, religion may influence whether or not procedures such as transplants and autopsies will be done. Religion also influences bereavement, grief, mourning, and funeral practices of a particular individual. However, religion has lost its major impact on DDI in today's technologically advanced society because death often takes place outside the home and inside professional medical facilities (Ross, 1984). "Death has been lifted from its context in a reliable, tightly knit social fabric into the realm of personal decisions, which are frequently subject to decrees by experts and institutions" (Ross, 1984, p. 4). Individuals and their families often "rebel" (Ross, 1984, p. 4) against these medical professionals.

The psychological component centers on theories mainly attributed to Sigmund Freud. According to Freud, the fear of death is not a clear cut phenomenon. It has an underlying meaning which says that death anxiety points to "*having difficulties with our basic instinctual life*" (Kastenbaum & Kastenbaum, 2000, p. 103). Individuals throughout history have engaged "in historical periods of death-denial, death-acceptance, and death-defiance" (Bendiksen, 1976, p. 60). As previously described, currently Americans are in a psychological phase of death denial in the 21st century.

Previous Studies on Social Service Direct Care Staff

Until recently, most studies discuss the individual with ID/MIH and their reactions to DDI and often neglect to address staff and family education, training, and support systems. There is universal agreement that supporting staff may be an initial step in helping individuals with ID/MIH grieve. Staff members often have good general knowledge of DDI. They often receive training on DDI from their employer. Not all staff confront structural barriers such as the lack of education and training from their social service agency (e.g., Read, 2005; Murray, et al., 2000; Hoover, et al., 2004-05).

A study of non-residential providers in the Upper Midwest states of North Dakota and Minnesota revealed that a minority of staff members believe individuals with ID/MIH are not capable of choosing their participation in death and dying rituals. Their mentality reflects a belief that staff and family members "know best" when it involves death and dying ritual participation. If the individuals have education on DDI the staff and family members may support a choice of participation. Meanwhile, a majority of staff believe that the individuals are able to choose whether or not to participate in death and dying rituals (Hoover, et al., 2004-05).

A study by Read (2005) recommends that a "model to facilitate healthy grief work" (p. 35) includes the components of education, participation, and facilitation. Education is defined as "helping people to understand about loss, change, grief and death in formal (educational curriculum) and informal ways" (Read, 2005 p. 35). The philosophy behind education mirrors the life cycle approach and other popular grief and loss aides. Read (2005) theorizes that participation is "nurturing a healthy emotional response" which is "achieved by proactive support" (p. 35). Facilitation is "reactive support following a loss

or death" (Read, 2005, p. 35). Read (2005) says that facilitation "involves a whole host of skills from the professional career, incorporating active listening, perception and observation skills; communicating in a meaningful way and having the knowledge base which accompany the development of these skills" (p. 36). The study further explores these concepts by highlighting a "17 point checklist devised to assess what services are available" (Read, 2005, p. 37).

A final study by Murray et al. (2000) cites factors relating to why people with learning disabilities often are not given adequate support. First, DCS have their own personal experiences with death. As a result, they may have their own personal fears of death (Murray et al., 2000). Murray et al. (2000) cites a "second factor which relates to a lack of staff knowledge and understanding about the processes associated with the experience of bereavement" (p. 79). The study indicates staff generally possess good knowledge about grieving and possible bereavement reactions of the individuals that they serve.

Conclusion

DDI are just recently recognized as important issues worthy of study in the social work arena. These issues deserve special attention because they have the potential to negatively impact the mental health of individuals. Counseling needs should be handled by professionals because loss issues often cause mental health problems. Social service agencies may train and educate their DCS and the individual's family. A literature review suggests that DCS and to a lesser degree, family members, are key players in the lives of these individuals and their ability to process the death and dying situations.

CHAPTER THREE: METHODS

This chapter answers questions about research methodology for the project. Basic questions such as research and ethics are posed. The purpose of this study was to examine GLI and DDI and how they relate to the self-observations of DCS when working with their clientele. The first objective was to establish what the relationship is between DCS and clientele. The second objective was to discover what role knowledge and training play in the overall social services picture.

Research Questions

In this study I answered the following research questions related to DCS and their interactions with individuals whom they serve. First, what general knowledge do DCS members have of GLI? Do DCS accurately gauge the individuals with ID/MHI and their ability to deal with the consequences of death and dying situations? Second, to what degree do social service agencies attempt to address DDI with staff through training and education programs? To what degree are staff adequately trained to recognize the psychiatric signs and symptoms of grief from loss? How routinely do agencies include training and education on grief and loss issues for DCS? Finally, what personal attitudes do DCS have about DDI and how does this influence their ability to handle GLI when presented with these issues on the job?

These research questions will be answered by research participants via an interview on DDI and GLI (see Appendix A). Questions were developed using a comprehensive literature review and knowledge of DDI as seen in the social services arena. The first question of the interview focuses on what qualities direct care staff as individuals feel that

they possess. Other questions focus on professional knowledge, training and education and they attempt to answer what the DCS knows about DDI and GLI. The final question centers on the DCS' personal philosophy of death. Questions in this section focus on spirituality, religion, mortality, and a general belief in the afterlife. It basically answers what the DCS's personal attitudes toward the importance of acknowledging DDI and GLI in their daily jobs. Finally, participants were also invited to make comments at the end of the interview.

Research Methodology

The literature indicates that DCS members generally have good knowledge of DDI. However, some staff may face service limitations due to structural constraints within the agency. This research study utilized qualitative methods. An interview was developed from a comprehensive literature review of GLI surrounding individuals with ID/MHI and their DCS. Open-ended questions were used throughout the interviews.

Data Collection

Data collection started with a project notification letter to agencies (see Appendix B). Four residential service providers from Cass County, North Dakota and Clay County, Minnesota were chosen randomly for the survey mailings. The researcher made a follow-up phone call several days after mailing the letter. The primary goal was to answer questions that may arise from the notification letter. A secondary goal was to schedule a meeting with each agency human resource director to gain project approval. Employers placed letters to potential interviewees in mailboxes at their respective agencies. The interviews took place at a private room at the interviewee's workplace on January 18,

2012, January 25, 2012, and February. 2, 2012. Each interviewee signed a consent form (see Appendix C). Then, interviews were recorded by a tape recorder and by taking notes. Interviewees took place approximately from nine to twenty minutes in duration.

Data Analysis

Data analysis for the questionnaire utilized qualitative methods. The open-ended questions were analyzed through a coding process. Themes emerged from the data and the researcher grouped them into categories using color coding. This process is called emergent theme content analysis. Each interview was transcribed from its recorded state. A line by line coding process was used to code each typed interview. This process provided the researcher with dimensions and properties of the emerging themes throughout the analysis and coding process (Strauss & Corbin, 1998).

Research Population

The target population for this study was the DCS of residential service providers who work with adult people who have ID/MHI. The DCS are those individuals who work with their clientele on a daily or weekly basis in their home. Social service case managers often heavily rely on DCS for their information on an individual's progress. DCS often are the only people that have regular contact with the clientele. DCS for this study were from a social service agency from one city of the upper Midwest which included Fargo, North Dakota. Interviewee characteristics varied based on gender, roles, and education (see Table 1).

Table 1

Interviewee Population Characteristics

Interviewee Characteristics	N	%
Gender		
Male	1	10.0
Female	9	90.0
Total	10	100.0
Role		
Supervisor	4	40.0
Worker	6	60.0
Total	10	100.0
Education		
< College	2	20.0
College degree	8	80.0
Total	10	100.0

Methodological Issues

Methodological issues included saturation and recording and note taking.

Saturation involves collecting enough information from the interviews where no new

information could be collected from doing other interviews (Struass & Corbin, 1998). The

employer may not want to participate due to fearing unpleasant results or the need to make

unwanted improvement in their company. The employee may fear some imaged or real

retribution for participation in the project or they simply may not want to talk about a

sensitive topic.

Recording and note taking pose their own unique problems. As the researcher I

prefer to conduct the interviews using both techniques. First, technical difficulties could

occur with the tape recorder. I could keep a second one on hand as a backup. Second, note

taking is a simple matter of bring enough supplies along as well. My third consideration

would be if the interviewee allows the use of these methods. Some people do not like tape

recorders and may only allow note taking during the sessions.

There were other methodological challenges. Employees from several different

agencies did not show interest in the project. Additionally, phone calls from several

agencies were not returned.

Special Considerations of Social Service/Grief and Loss Research

Social service research and grief and loss research share some common qualities.

Both types of research require a special sensitivity to the needs of the researcher and the

research subject. Judy Davison (2004) says that "Research on sensitive topics that

prioritises the subjective experiences of devalued individuals from marginalized groups is

well suited to a feminist interpretive inquiry" (p. 384). The feminist method of inquiry

would be especially well suited towards the topic of DDI for individuals with ID/MHI

(Davison, 2004; Harding & Norberg, 2005; Lee & Renzetti, 1993). The researcher may

also use journaling as a stress reliever and a gateway to "emotional reflexivity" (Davison,

2004, p. 379). Emotional reflexivity requires a "conscious" (Golombisky, 2006, p. 166)

awareness of the self.

A researcher undertaking social service research must consider several issues. First,

social work has a unique value system from other human service fields. Ian Butler (2003)

indicates that "good social work research means doing social work research with a

confident and robust understanding of the values on which social work itself is predicated"

(p. 25). Initial licensure and license renewal hinge upon following a strict code of ethics for

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social workers. Social workers who do social services research may have conflicting roles as social worker and researcher. However, these conflicts may be resolved by using feminist methods of inquiry during the research process such as life story and narratives (Davison, 2004; Golombisky, 2006).

As with social service research, a researcher undertaking grief and loss research requires utilizing emotional reflexivity and the research faces many challenges. Each researcher of grief and loss issues must consider their own personal value system regarding DDI. The subjective nature of the researcher's and research subject's value systems often taints the research findings especially with grief and loss research (Edwards,1993; Rowling, 1999). Other considerations involve preventing emotional harm to the research subject who must be encouraged to seek counseling services if the researcher feels harm has been committed during the research process. Understanding these potential problems facilitates a methodologically sound study. This project received approval from the NDSU Institutional Review Board.

CHAPTER FOUR: FINDINGS

Interviews took place at a local social service agency on January 18, 2012, January 25, 2012, and February 2, 2012. Five questions were asked of participants. Questions used in the interview were based on a comprehensive literature review on death and dying issues and grief and loss issues. Data collection was done by audio recording the interviews and taking notes during the interviews.

Interviews were transcribed using a word-by-word method. Data analysis used the emergent theme content analysis method. Themes emerged from the data or the words spoken by the interviewees. Upon further analysis, the themes were color coded. Some themes were collapsed into similar categories. Other methods of data analysis included writing memos, making notes about the data, raising thoughts about the data, and asking more questions about the data.

This chapter reports on the themes that emerged from the content analysis of the interviewees transcripts. The first question was "In what ways do you work with people who have mental illness/intellectual disability?" The second question was "What is your experience with GLI or DDI in your agency?" The third question was "What are the general needs of your clientele regarding DDI and GLI by comparison to the general population?" The fourth question was "What is your general philosophy about DDI issues?" The final question was "What is your educational background and what training have you received from your agency on death and dying issues? On grief and loss issues?"

Question One: Staff's Work with Individuals

Question One asks, "In what ways do you work with people who have mental illness/intellectual disability?" The question asks the interviewee to describe their daily duties with their clientele. It gives the interviewer insight into a typical day of the life of the DCS. There are five emergent themes for Question One. They are (1) help with communication, (2) help maintaining friendships, (3) help meeting everyday needs, (4) help living a full life, and (5) help as a supervisor.

In help with communication, it is part of a DCS staff to help make sure the client communicates his or her wishes. It is an important part of life. One of the interviewees said that she "help(s) them communicate in a way that is pleasing to them" and "help(s) them communicate with others."

As a second theme, when helping to maintain friendships, staff facilitate this theme by providing socialization opportunities in the community. As one interviewee said "being active in the community" helps maintain these friendships. At the same time, clientele remain in contact with their families.

The third theme, help meeting everyday needs, encompasses a wide variety of activities. Staff cook, clean, buy groceries and give medications among many other tasks. One staff describes his duties as the following:

> I help them with their home living. I'm like their residential staff. I assist them with daily hygiene and grooming and preparing for work each morning. Shopping and home maintenance…

Another interviewee says she is involved in "pretty much all aspects of their life".

Fourth, as seen by previous themes in Question One, <u>staff help clients live a full life</u>. They meet every day needs, help communicate, and help maintain friendships. One interviewee comments that it is part of her job to "help them live their lives to the fullest." According to the interviewee, living life to the fullest includes receiving social services "in a manner that is pleasing to them".

The final theme is <u>help as a supervisor</u>. Supervisors often are in charge of various apartments with certain clientele living in them. These apartments have DCS that work with the clientele and DCS report directly to the apartment supervisor about that particular client. Four out of ten interviewees were supervisors or site managers. Being a supervisor also entails being a DCS. "I am a direct support manager. So I manage a department. Then, I also do direct care," said one interviewee.

Question Two: Past Experiences of the Staff

Question Two asks, "What is your past experience with GLI or DDI in your agency?" It asks interviewees to discuss their experiences because these experiences may affect how the interviewees interact with the clients in DDI/GLI. There are seven themes. They are (1) presence at death, (2) number of deaths, (3) emotion related to the death experience, (4) attachment to the deceased, (5) family of the clientele, (6) grieving as a process, and (7) staff transitions.

First, <u>presence at death</u> refers to whether or not the interviewee was there during the dying process. One interviewee describes presence as: "I was actually in the room when they took her off the ventilator and stuff." Most interviewees did not report being in the room when their client died.

Second, number of deaths refers to the number of deaths experienced by the interviewee at the social service agency. The deaths experienced by the interviewees ranged from one to three.

For the third theme, emotion related to the death experience is any emotion related to a death and dying experience and attachment is closeness to the client or the dying person. Emotion related to the death experience indicates strong attachment to the deceased or the fourth theme. One interviewee said of one of her clientele, "I really enjoyed her." She goes on to say "that was really sad when she passed away. I think about her a lot still."

The fifth theme, family, refers to family of the clientele. Staff often become close like family members to their clients. Family often rely on staff to take care of the many daily tasks. As one interviewee put it, "The families of the people that passed away were very very understanding that we were staff. They were family but kinda staff and family too."

The sixth theme, grieving as a process, goes along with the death and dying process. One interviewee describes the grieving process.

> It's hard seeing a person upset. It's like seeing a child upset. How can I help you? You have to go through the process to work through it. Sometimes it's hard to sit and watch the person work through the grieving process when nothing you say can make them happy or make them feel better.

The final theme is staff transitions. Staff transitions take place frequently in a social service agency. They may take a toll on the clients and cause a grieving process One interviewee said "It is very hard on the people we support at times depending on how close they were to that staff".

Question Three: General Needs of the Clientele as Perceived by the Staff

Question Three asks, "What are the general needs of your clientele regarding DDI and GLI by comparison to the general population?" This question gauges whether or not interviewees view client's needs differently when dealing with DDI/GLI. There are three themes. They are (1) communication, (2) education, and the (3) grieving process. Barriers exist for clientele when navigating the social world, especially when dealing with DDI and GLI. One interviewee said that the "biggest barrier for them is when someone that they know passes away there's not a lot a resources for people with disabilities."

Communication and education are barriers. The first theme, communication, is a consistent theme throughout the interviewees. One interviewee suggests "Photo album, scrapbooking, (and) keeping memories alive" as key to communication. Another interviewee suggests "work(ing) really close with them (clientele) to try to explain things." The second theme, Education as with resources, is scarce for people with disabilities. One interviewee said education should be "discussed in a way that people may understand." She goes on to say that death should be taught in a more concrete way rather than abstract one.

The final theme is the grieving process. Grief is a process all people experience. The grieving process does "affect them (clientele) more than a person in normal society," according to one interviewee. Clientele "Need(sic) more time to get through the grief process (and) have(sic) continuous support to get through the process."

Question Four: General Philosophy about Death and Dying Issues/Grief and Loss Issues

Question Four asks "What is your general philosophy about DDI issues?" The question asks about the interviewees' philosophy about DDI/GLI to gauge whether or not it effects how the interviewees work with people who have ID/MHI.. There were five themes. They are (1) connection, (2) shared experiences, (3) balance, (4) life, and (5) belief in afterlife.

The first four themes, connection, shared experiences, balance, and life, are all closely related. One interviewee describes the themes as the following

> All life is a cycle and a transition. We lose something, but there's a balance…It's sad to see someone go, to lose that connection, but it's a beautiful thing that they ever lived and that you ever shared the experiences.

The final theme is belief in the afterlife. The afterlife was a dominant theme in this question. Most of the interviewees had some belief in the afterlife. One interviewee compared the afterlife to a seed. "We look at a seed and it looks dead. We live on through a spiritual body..."

Question Five: Education and Training of Staff

Question Five asks, "What is your educational background and what training have you received from your agency on death and dying issues? On grief and loss issues?" The question asks about training and education because they may affect how the interviewees view DDI/GLI. There are two themes. The themes for this question are education and training. Education describes an interviewee's education at an institution such as a college. Degrees range from psychology to gerontology. Training refers to education received at the social service agency on DDI and GLI.

CHAPTER FIVE: DISCUSSION

The purpose of this study was to examine GLI and DDI and how they relate to the self-observations of DCS when working with their clientele. The first objective was to establish what the relationship is between DCS and clientele. The second objective was to discover what role knowledge and training play in the overall social services picture.

Results of the findings indicate that there are differences among supervisors and staff because of the independent variables philosophy/religion/spirituality, educational background, and past experiences. Supervisors faced unique personal as well as professional challenges when dealing with DDI and GLI. They dealt with DDI and GLI while helping their co-workers cope at the same time.

Discussion of the Results

Question One and Three ask how do the interviewees respond to people with MHI/ID? And to GLI/DDI? Question Two asks about past DDI experiences, Question Four asks about philosophy, religious background and spirituality, and Question Five asks about education and training (see Figure 1).

There were certain types of responses to the questions. Question One had three types of responses. They were official capacity/role, tasks/activities, and results of their involvement. Interviewees serve as friends and/or supervisors in their official capacity/role. Tasks/activities is about communicating, meeting needs, completing daily tasks, and providing direct care. Involvement, the clients will have a full life.
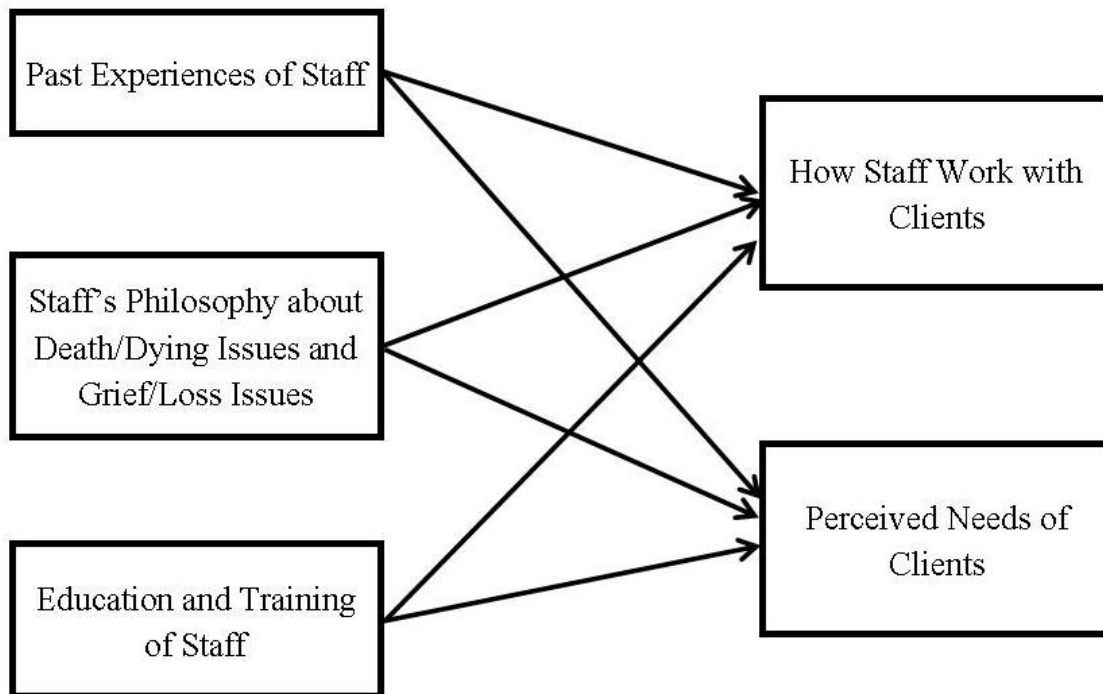
Figure 1. Interview Question Response Types

Question Two had three responses. They were past experience with loss, but not death, experience with death and loss, and experience with no death or loss. In the category past experience with loss, but not death interviewees experienced loss of staff and staff transitions. Supervisors helped their staff with the staff's responses to DDI/GLI in past experiences with death and loss. With no death or loss, one interviewee gave a profound answer to Question Four. There was sadness in his answer but he understood the life process.

Question Three had two types of responses and Question Five had one type of response. Its' responses are described as barriers to individuals with MHI/ID and the process they go through when experiencing a loss. Barriers noted are education and communication and grief is the process. Question Five responses are described as skills or education and training.

Question Four had three response types. They are philosophical, religious, and spiritual. Philosophical types represent believing in a life cycle. Religious types share a belief in some form of religion. Spiritual types represent creating a balance in life, shared experiences and connections, and a belief or non-belief in the afterlife.

Interviewees responded differently to the questions because some were supervisors (n=4) and others provided direct care only (n=6). Supervisors often face dual challenges when dealing with DDI and GLI. For example, one supervisor noted past experiences of helping her staff deal with DDI and dealing with her issues at the same time. The same supervisor also said she had a harder time dealing with workplace death than personal ones.

Some interviewees practice methods as set forth in the literature review. One interviewee practices art therapy through scrapbooking and keeping photo albums. She also observes anniversaries and encourages clientele to talk about the deceased. Others practice care for the clientele by encouraging the funeral arrangements for clientele before it is necessary.

I found that all interviewees agreed on some level that clientele have greater needs than those of the general population when it comes to DDI and GLI. According to symbolic interactionists LoConto & Arrington, (2007), this brings us back to the concept of sociality, a "key to adjustment during the grieving process" (LoConto & Jones-Pruett, 2008, p. 27). Sociality is different in people with ID/MHI because they do not develop as many social coping mechanisms to deal with DDI and GLI. As previously discussed, people with MHI/ID often face educational and communication barriers that make dealing with DDI and GLI difficult.

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I found that Question Four data references the life cycle. This reference is similar to the program that Mappin & Hanlon, 2005 and Hedger & Smith, 1993, refer to in their life cycle programs. The life cycle is used as a teaching tool for people with MHI/ID when dealing with DDI/GLI.

Family, DCS and clients all have specific interactions during the death and dying and grief and loss processes. This is clear in the Symbolic Interactionism concept of sociality, as previously discussed. Clients do not often have multiple identities and they must cope with DDI and GLI with fewer skills than the general population. One of Goffman's theories suggests that clients and DCS have specific role expectations from one another in an institutional setting. This may hold true for a residential setting as well.

Awareness theory focuses on types of interactions between the dying patient and his team of healthcare professionals. The types were open, mutual pretense, suspicion awareness, and closed. In open, the patient knows he/she is dying as does the DCS. In mutual pretense, both client and DCS know but do not talk about impending death. In suspicion awareness the patient is suspicious of the impending death, but confirms it with DCS. In closed awareness, the patient does know about impending death, but the DCS does know.

Awareness theory was helpful when examining the data. Two of the interviewees had worked with dying clients. Because it was a residential setting, the setting was open awareness. Both DCS and client knew of the impending death. There was no indication that the awareness context had changed and it had always been open.

CHAPTER SIX: CONCLUSION

There is a lack of training and education about DDI and GLI at the typical social service agencies. GLI and DDI are ignored and staff and clientele suffer the consequences. Training and Education need to be done on a proactive basis for both DCS and clientele.

Application for Practitioners

Training and education are key factors for practitioners. They are done on an as needed basis only. They should be done proactively so that DCS and their supervisors are able to cope appropriately with DDI and GLI. This in turn will the clientele deal with DDI and GLI and lift education and communication barriers. This will provide DCs to effectively do their jobs and it will help with retention.

Implications for Additional Research and Policymakers

This study serves as a current snapshot of current trends and lines of thought on DDI and GLI. Further study is needed because of this study's limitations. The study is small in scale and it took place at only one local agency. More DCS need to be interviewed to paint a clearer picture of the differences between supervisors and DCS. Agency policies may vary as well.

The study only shows one side of the puzzle. People with ID/MHI were not interviewed. Interviews with them could provide further clues as to what may be done to help them. Longer interviews with more probing questions could be done with DCS.

All interviewees indicate that DDI and GLI training is done on an as needed basis. If there is a death, the training is done. However, no training is given for when a staff leaves a client. On the job training and some type of certification for DDI and GLI should

be required for all employees. There are some training modules through Minot State

University available to staff. However, these manuals focus on aging as a topic rather than

DDI or GLI. This is the perfect mode to convey the training to individuals.

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APPENDIX A: INTERVIEW FORM

Instructions: *This interview is intended to gain insight into residential service providers, specifically direct care staff of adults with intellectual disability (ID) and/or mental health issues (MHI), and their knowledge, education, and training on grief and loss issues (GLI) and death and dying issues (DDI). Possible benefits are being able to support those with ID/MHI.in DD/GL situations. This may serve to strengthen to serve the direct care person's overall role in the agency. Participation is voluntary and you may choose to withdraw from the study at any time. .The interview will take about 10-15 minutes.*

1. In what ways do you work with people who have mental illness/intellectual disability?

2. What is your experience with GLI or DDI in your agency? (Probes: What are some positive aspects? What are some negative aspects? General outcomes?)

3. What are the general needs of your clientele regarding DDI and GLI by comparison to the general population?

4. What is your general philosophy about DDI? (Probes: Spirituality? Religion? Morality? General belief in the afterlife?)

5. What is your educational background and what training have you received from your agency on DDI? On GLI?

APPENDIX B: ACCEPTANCE LETTER FOR AGENCIES

Dear Sir or Madam:

I am a graduate student studying Sociology at North Dakota State University and have worked as a direct care staff person at a local social service agency. I am conducting a project on death and dying issues and their impacts on the direct care staff of adult individuals with disabilities and/or mental illness. The focus of the project is to learn how direct care staff deal with grief and loss situations and how they may help those whom they serve better cope when these situations arise. Death and dying issues area relatively new area of study in the social services arena. This study serves to help break down existing barriers and provide new insight into the area of the direct caregiver and their role in the social services.

As an administrator in a social service agency, I am asking your assistance in this project. Your agency has been selected, along with four other agencies, because you provide services to adults with intellectual and/or physical disabilities. Your agency's unique insight will provide valuable information for my project.

Here's what I requesting from you: First, I will provide to you in an unsealed envelope a list of questions I'll ask in my interviews with direct care staff. Also in the envelope is my contact information. Please select ten of your direct care staff who work with individuals with mental illness and/or physical disabilities and deliver envelopes to them.They would be asked to contact be voluntarily within the week to arrange for a private interview in a discrete location at their convenience. I would certainly appreciate your participation.

Your agency's participation is voluntary. If you decide to participate, you are free to withdraw you consent and to discontinue at any time. Overall results from this study will be available upon request.

Individual information collected in this study will remain confidential and will not be reported. Interviews will be audio recorded and only a pseudonym will be used to label the interviews. All interview information will be safeguarded during the data analysis process then promptly removed and destroyed to protect their privacy.

You should feel free to ask questions now or at any time during the study. If you have any questions about this study, you can contact Elizabeth Wood, 701-429-7789, at e.wood@ndsu.edu. If you have any questions about the rights of human research participants, or wish to report a research related problem or injury, contact the NDSU IRB Office at (701) 231-8908 or ndsu.irb@ndsu.edu.

APPENDIX C: INTERVIEWEE CONSENT FORM

Dear Sir or Madam**,**

      I am a graduate student studying Sociology at North Dakota State University and I have worked as a direct staff person at a local social service agency. I am writing my master's thesis on death and dying issues and the impact on the direct care staff of adult individuals with intellectual disabilities and/or mental illness. The focus of the project is learning how direct care staff deal with grief and loss scenarios and how they may help the adult individual they serve cope better when these situations arise.

      As a former direct care staff member and a researcher, I feel that grief and loss issues impact direct care staff and the adult individuals that they serve in all facets of life. Helping direct care staff cope with these problems is just one piece to the complex social services puzzle,

      As a former direct care staff, I am asking for your participation in this project. You have been selected because you work with adults with intellectual/physical disabilities at your agency. Your unique insight will provide valuable information for my project.

      Death and dying issues are a relatively new area of study in the social services arena. This study serves to help break down existing barriers and provide new insight into the area of the direct care giver and their role in the social services. Your participation will facilitate this purpose.

      This interview is based on a comprehensive literature review on grief and loss issues. It will take about 15 minutes to complete. Your participation is voluntary and you may withdraw at any time. Your decision whether or not to participate will not affect your present or future relationship with your employer, NDSU, or any other benefits to which you are otherwise entitled. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time.

      Individual information collected in this study will remain confidential and will not be reported. Interviews will be audio recorded and only a pseudonym will be used to label the interviews. All interview information will be safeguarded during the data analysis process then promptly destroyed to protect their privacy.

      You should feel free to ask questions now or at any time during the study. If you have any questions about this study, contact Dr. Gary Goreham, Ms. Elizabeth Wood's advisor at 231-8657 or gary.goreham@ndsu.edu. If you have any questions about the rights of human research participants, or wish to report a research related problem please contact the NDSU IRB Office at 231-8908 or ndsu.irb@irb.edu.