

DEATH AND GRIEF AS EXPERIENCED BY ADULTS WITH DEVELOPMENTAL DISABILITIES: INITIAL EXPLORATIONS*

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ABSTRACT

The experiences of persons with developmental disabilities (DD) in two northern-tier states were studied on an exploratory basis. Overall, the analysis reveals that caregivers in residential facilities believed that persons with DD (primarily global cognitive disabilities) benefit from the same grief processing rituals as other individuals. Some conflicting attitudes were revealed, however. Specifically, many respondents expressed a sense that caregivers (or family members) "know best" when individuals with disabilities prove "ready" to experience the activities and ritual surrounding

*The terms "DD" and "global cognitive deficits" are employed in this article to represent the condition formerly labeled "mental retardation." This expression refers to general cognitive deficits occurring simultaneously with significantly low adaptive behavior performance. The former construct is typically quantified by scores on general cognitive functioning instruments falling two standard deviations below the mean (i.e., "IQs" below 70). Typically, global or general intelligence scores are reported as standard scores with $M = 100$ and $SD = 15$. Clinicians measure the latter construct via adaptive behavior rating scales and/or direct observation of performance in such domains as language, academic, recreation, shopping, and self-care. The term "mental retardation" is only employed in the article either when an item specifically referred to this term or when respondents employed it. Otherwise, we used the term developmental disabilities (DD).

loved ones' deaths. In addition, many respondents argued that clients with cognitive disabilities ought to be educated ahead of time as to what happens during the death and dying process. Primary care providers reported very few overt behavioral changes, though four clients in 10 were observed to cry more frequently (for more than 1 month) and about one-fifth reportedly experienced changes in sleep/wake patterns. Initial evidence emerged that staff training patterns varied by facility, not with years of service.

Everyone, including persons with developmental disabilities (DD), eventually experiences grief resulting from a variety of losses. Some grief-inducing events include loss of a familiar place (such as a home, a city, or state of residence), loss of physical or cognitive abilities due to accident or illness, or the death of a significant other (family member, friend, care provider). The grief due to the death of significant person may bring about one of the most intense and difficult responses. Persons with DD experiencing this type of grief may require considerable support (Bonell-Pascual et al., 1999; Lavin, 1989).

Though grief may be universal, the manner in which it plays out remains personal. A person's beliefs, social condition, and familial situation all significantly affect the intensity of feeling engendered by loss (Hollins, 1995; Myreddi & Jayanthi, 1993). For some, the death of a loved one may produce feelings of fear, sadness, or even confusion (Lavin, 1989). In contrast, others may manifest indifference or even relief (Yanok & Beifus, 1993).

A grieving individual requires support and understanding from those in his or her life in order to navigate the process in a healthy manner. Because support is so important, team members working in the best interest of adults with DD (including family members, service providers, and other care partners), must recognize grief due to the death of a significant person as a primary and significant life event (Hollins, 1995; Lipe-Goodson & Goebel, 1983). Support for an adult with a developmental disability who is grieving means that significant others make their presence positively felt; helping professionals might be called upon to listen and to demonstrate empathy. At times, residential care providers may function as the *only* candidates for providing this support to grieving clients.

Culturally sanctioned rites and rituals afford considerable support for bereaved individuals. Preparation for such events as funerals and participation in the rites is typically an option for most adults. Rituals surrounding the end of life help people understand and accept death's reality; they also create situations where mourners offer one another emotional support and opportunities to talk about the decedent's life and death, a process many report to find comforting. That is, death-related rites help people overtly express grief and provide opportunities for healthy mourning, in effect lending structure to the death experience (NFDA, 1997). Investigators have shown that participation in death and dying

rituals facilitates healthy grieving both in persons with and without cognitive disabilities (Luchterhand & Murphy, 1998; Worden, 1996).

Caregivers' attitudes toward and knowledge of mourning obviously come into play in terms of the options offered to adults with DD. Team members working with grieving adults with DD must not only tolerate grieving but also understand and affirm it. Care providers also need to seek or suggest resources (such as counseling) if they deem such extra support necessary. If team members feel uncomfortable around expressions of grief and are unable to adequately support it, they may negatively affect a consumer's ability to mourn meaningfully (Deutsch, 1985).

Resistance to the participation of persons with DD in culturally normative activities may reflect their devalued status in nearly all life domains (Wolfensberger, 1972, 1983)—including mourning (Deutsch, 1985). People with DD are often forgotten mourners; in effect, significant others may disenfranchise them (Doka, 1989) from the process (Schwebach, 1992, as cited in Thornton & Zanich, 2002). Disenfranchised persons may not be offered support because others may not perceive them as requiring assistance or even needing to mourn. This socially sanctioned lack of support is likely to complicate adjustment to loss. The term disenfranchisement is particularly apt as a metaphor, referring as it does to preventing individuals from making choices and expressing preferences.

Based on a review of literature and Doka's conceptualization, Thornton and Zanich (2002) supported a taxonomy consisting of three classes of disenfranchised grief. First, an extrafamilial death (e.g., a noncustodial parent) may not "be socially recognized as a context for grief" (p. 80), and thus not worthy of support. Second, the loss itself may not be deemed worthy of grief as in, for example, the death of a pet. Finally, and most pertinent to the present discussion, potential supporters may disenfranchise the individual experiencing a loss because the person may not seem capable of experiencing grief in a manner expected by outside observers. Thornton and Zanich noted that, despite a lack of empirical work, existing data suggests that both college students and service providers viewed persons with DD as needing to grieve but also that these individuals required some protection from the process (Schwebach, 1992).

It is vital that people with and without DD confront issues of grief, loss, and mourning. Huston (1992) wrote that, "Grieving without mourning is unhealthy and can lead to emotional or physical complications—even death" (p. 9). Little is known, however, about the nature of the loss and grief experience for persons with mental disabilities living in residential programs. We designed this study as an initial effort to investigate the views of residential care providers. Not only are such staff members in a position to support individuals with disabilities in processing grief, but also they are also useful informants as to what takes place when a client suffers a loss. We posed questions about death and grieving, specifically how care givers should handle such experiences on the part of their clients with DD. The research here can best be described as preliminary,

exploratory, and descriptive. Thus, no a priori hypotheses were tested, though we employed both qualitative and quantitative methods (including some exploratory inferential techniques). Despite the relatively small number of surveys returned, the sheer amount of written data provide useful preliminary insights into the attitudes of residential service providers toward the grief experiences of consumers.

METHOD

Instrument

Demographic information regarding the characteristics of managers and counselors at residential facilities was elicited via an instrument designed specifically for the present investigation. We included a set of items arranged in a 5-choice Likert format. Via the Likert items, we elicited staff members' attitudes about dealing with death and grief issues in clients who had suffered loss. We asked residential supervisors who had not worked with such an individual to respond "as you would for a typical client in your agency that might in the future suffer loss." We requested that all respondents react to these statements whether or not they had worked with a disabled individual who had undergone such an experience.

We designed a second set of (yes–no) responses to reflect actual occurrences upon the death of a person friendly with or closely related to a client served by the agency. We asked respondents to skip this section unless they had worked directly with an individual who had suffered "the loss of a friend or close relative" within the past 12 months. The yes–no items also included a "don't know" choice (For example, "The individual was part of the small group of people who planned the funeral").

A final section included items related to the client suffering the loss. This included age, estimates of functioning level, sex, and estimates of performance decrements, if any, in the period following the death. We provided respondents space to respond in writing at the end of the instrument. We requested that one staff member complete the instrument on behalf of the whole facility; thus, the level of analysis is essentially facilities.

Participants

Residential Staff Members

State officials in North Dakota and northwest Minnesota provided lists of residential facilities serving persons with DD, primarily cognitive deficits. We sent surveys to a sample of about 25% of each list, with a follow-up mailing sent about one month later. We selected randomly, though proportionately, from

the strata represented by states and regions within states. Because of the length of the instrument and the requirement for the provision of written explanations, the data collection was much more similar to a structured (albeit written) interview than to a typical survey.

In the final sample, 12 (21.1%) responses were drawn from North Dakota and 45 (78.9%) from northwestern Minnesota, over-representing North Dakota by about 8% (when going by population figures). Staff members responding to the instrument averaged 40.91 years of age ($SD = 8.93$). Respondents proved to be an experienced group with a mean of about 14.5 years working with persons with DD (14.47, $SD = 6.42$, range = 1–31). Proportionately, many more females ($F = 43$, 75.4%) completed surveys for their facilities than did males (14, 24.6%).

Persons with DD Who Had Recently Suffered Loss

The 48 individuals who had suffered loss in the 12 months preceding data collection averaged 45.2 years of age ($SD = 10.6$, range = 30–65). Informants had known the individuals an average of 9.3 years ($SD = 5.66$, range = 1–22). Twenty-three clients who had suffered loss were reportedly male (47.9%) and 25 female (52.1%).

We asked for estimates of the individuals' intellectual and adaptive functioning level using the pre-1992 (mental retardation; MR) model, thinking that more staff members would be familiar with that system. Of those loss sufferers for whom staff members provided estimates, 15 were ranked as experiencing mild MR (31.3%), 13 moderate (27.1%), and 20 severe/profound (41.7%). Conditions manifested by clients other than cognitive disabilities included mental illness or behavioral disorders ($N = 8$, 29.6%), sensory impairments ($N = 3$, 11.1%), medical problems (4, 14.8%), and orthopedic disabilities (5, 18.5%).

Five categories of communication levels/systems were presented to respondents. Staff members reported that 31 individuals suffering bereavement (66.0%) communicated verbally, 10 individuals (21.3%) were reportedly nonverbal and used no clearly identifiable system to communicate. Four individuals (8.5%) employed augmentative systems; the remaining two individuals for whom data were available employed sign (4.3%).

Procedure

Cover letters and postage-prepaid return envelopes were sent along with two surveys to community residential facilities selected via the stratified random sampling described above. Small intermediate care facilities, long-term community care, and semi-independent living programs were sampled, not large public residential programs. Following two mailings, the final number of 57 useable surveys represented 48% of the 120 sent. Graduate students entered survey responses into SPSS for Windows (Version 11), via which descriptive and

inferential statistics were calculated. Transcripts of written comments were made and examined for themes.

Qualitative Analysis

The first author read all transcripts and coded staffers' written statements into raw categories. These were then combined to form themes, with some retained subcategories serving as sub-themes within the larger topics addressed by respondents. Several times, statements fit into more than one thematic grouping. In addition, respondents often wrote several statements that could be coded into multiple categories. The third author checked the category definitions and negotiated any disagreements with the first author until agreement was reached that all statements were categorized as having addressed one of the topics.

RESULTS

Bereaved Individuals

Of the 57 surveys returned, 49 reflected the loss of a loved one within one year of staff members' receipt of response packets. As discussed below, this may be taken as a very crude estimate of the number of residential programs per annum in which a client will suffer the loss of someone near to them.

The survey included an item related to temporal aspects of the death of someone close to clients with disabilities. Thirteen deaths proved to terminate lengthy illnesses (more than one year, 27.7%). Staff members selected "long illness (less than one year)" for another 13 individuals (27.7%), while another 21 individuals reportedly experienced the sudden/unexpected illness or accident of someone close to them (44.7%).

Attitude Items

We recoded both non-responses (to an individual item) and "don't know/does not apply" choices as missing data prior to calculating the means shown in descending order in Table 1. All respondents, including the 14% who had not worked with an individual with MR/DD suffering a recent loss, were asked to complete the Likert items. The items in Table 1 are presented in descending order with higher values (up to 5 points) representing higher levels of agreement.

Responses to the first three attitudinal items attained mean values above "agree" on the Likert scale and about 9 in 10 respondents agreed or strongly agreed. Two of the three variables dealt specifically with counseling and education regarding the death and dying experience ("talk about the experience" and "coached on the service"). A strong majority (about 3 in 4) agreed with the next three highest-rated items ("stay at funeral home as much as wish"; "educated or informed"; and "told when others are told"). Decidedly fewer (around half) agreed with the three

Table 1. Attitude Items Arranged in Descending Order by Level of Agreement (Higher = More)

Item	<i>N</i>	Mean	<i>SD</i>	% agree ^a
Staff encourage or affords the opportunity for the individual to talk about the death or dying process	54	4.39	.76	94.4
Individuals are allowed to remain at home, if they choose to, between the death and funeral	52	4.17	.71	86.5
The person suffering a loss should be coached on what will happen at the burial and/or funeral service	55	4.09	.85	87.3
The individual is encouraged or allowed to spend as much time at the funeral home during the visitation as he/she wishes	54	3.76	1.20	72.2
The individual was educated or informed about the dying process to the extent that s/he knows what to expect when it happened	51	3.65	1.07	74.5
The individual is told at approximately the same time as other family members or friends are told of the illness, accident, injury, or death	55	3.64	1.32	74.5
The individual is encouraged or allowed to spend as much time as they wished at the hospital or home where their loved one was staying while they were dying (if applicable)	48	3.48	1.17	52.1
The individual is told of all the facts and information available about the diagnosis, condition, and prognosis	53	3.25	1.22	58.5
One consistent healthcare provider should communicate with the individual during the dying process	56	3.23	1.08	42.9

^aPercent of those venturing an opinion who agreed or strongly agreed with the item.

choices obtaining the lowest mean values (“spend as much time at hospital as want”; “told of diagnosis and prognosis”; and “one consistent health care provider communicates with individual during the dying process”).

Correlations with Education/Prior Preparation

Upon a preliminary examination of written responses, it appeared that staff members tended to agree that individuals should participate *if they had been educated about the event in question ahead of time* (see qualitative section below). To test for a possible relationship between “attitudes toward client participation” and “preparation” we calculated product moment correlations between an item referring directly to preparation for death and dying experiences (“the individual was educated and informed”) and the other Likert items. Results are displayed in Table 2.

Staffers’ perceptions of their clients’ preparedness for death and dying events predicted ratings of agreement with five of eight participation items: “Receiving word of the experience,” “being told of the facts surrounding a terminal illness,” “talking about death,” “spending time at the funeral home,” and “spending time in the hospital with the dying individual” were all significantly positively correlated with a priori preparation for these events (even controlling for family-wide error rate via the Bonferroni method).

Participation in Specific Events

We designed a series of 12 items reflecting the experience of particular clients to a death and dying experience. The deaths of 49 “closely-related” individuals were documented in the data set. Responses of staff members to events in which

Table 2. Correlations between Attitude Items and Values for
“The Individual was Educated and Informed”

Item	Correlation	<i>p</i>
The individual is told at the same time as others	.49	< .001
Individual told of facts and diagnosis/prognosis	.45	.001
Staff encouraged individual to talk about death	.47	< .001
One health care provider talked with individual	.14	NS
Person suffering loss should be coached about funeral	.26	NS
Individuals allowed to stay home if they choose	.24	NS
Individual allowed to spend time at funeral home	.51	< .001
Individual allowed to spend time at hospital	.57	< .001

clients chose or were allowed to participate are shown in Table 3 arranged in descending order by participation frequency.

About four of five individuals with disabilities suffering loss attended funerals and memorial meals. A slightly lower percentage attended final rites (either burial or cremation). Less than half of the persons with DD reportedly participated in the other rites, rituals, and activities related to a loved one's death. Very few individuals helped plan the funeral (7%) or received counseling/support (3%).

Training

Residential staffers were asked to respond to an item reflecting whether they had received training at their facility in dealing with death and dying. Of the

Table 3. Client Participation Items in Descending Order by Frequency of "Yes" Responses

Item	<i>N</i> ^a	<i>N</i> ^b	% Yes
The individual attended the funeral	36	47	81.0
The individual participated in a meal before or after the burial or memorial service with other mourners	37	47	78.7
The individual attended burial or other final rites	27	45	60.0
The individual sent flowers	19	43	44.2
The individual received flowers	18	45	40.0
A minister or spiritual leader visited the individual	13	41	31.7
The individual attended a death or dying class	7	43	16.3
The individual was with [the dying person] as they died	7	47	14.9
The individual talked with a counselor or psychologist during the period of death and dying	5	43	11.6
The individual was part of a small group of people who planned the funeral	3	43	7.0
The individual attended a group counseling session or support group for people experiencing grief and mourning	2	46	4.3

^aNumber responding (excluding "don't know"). ^bNumber selecting "yes."

46 who selected a response, 31 indicated that they had received such training (67.4%); the remaining third (32.6%) had not.

An independent-groups *t* was calculated whereby “years in the field” was treated as a dependent measure. We performed this analysis in order to determine whether staff members that had received training had been employed for a longer period of time, thus experiencing a greater raw chance of having received such training. No significant difference was observed between those trained and those not trained when we employed “years service” as a dependent variable (dv) (Independent Samples *t*, $df = 44$, $t = 1.54$, $p = .130$).

Change of Functioning

In an attempt to understand the effects of a loved one’s death on individuals diagnosed with DD, we asked staff informants to rate the degree of change following the death of a loved one in five domains, including sleep patterns and dreaming, eating behavior, crying or dysphoria (beyond one month), and need for medication.

We did not disaggregate data by disability category because independent samples *t*-tests calculated for the five variables (treated as dv’s) produced no significant differences between disability levels, especially given the need for the Bonferroni adjustment for family-wide error rate (p ’s ranged from .14 (sleep changed) to .53 (eating habits changed)).

If scores from the midpoint of the scale and up (i.e., values of 3, 4, or 5, with higher values reflecting more behavioral change) are taken as representing significant changes, then staff members viewed the greatest proportion of individuals as changing in the areas of mood (crying or sadness lasting more than a month, $N = 19$, 40.4% rated as “changing”, $M = 2.17$, $SD = 1.27$), closely followed by sleep patterns ($N = 11$, 23.9%, $M = 1.96$, $SD = 1.03$). Either less change or less noticeable change occurred in the areas of dreams ($N = 6$, 13.0%, $M = 1.67$, $SD = 0.94$), eating habits ($N = 5$, 10.6%, $M = 1.57$, $SD = 0.90$), and medication requirements ($N = 6$, 13.3%, $M = 1.56$, $SD = 1.06$). In each of the latter three domains, care providers observed significant changes in less than one in five clients.

Qualitative Analysis

Utilizing the procedures outlined above, responses were categorized into 16 themes initially. In performing the analysis, we viewed several of the themes as related and re-combined them. For the sake of convenience, we lay these out below in descending order by the number of times they were addressed by respondents.

Theme One: Decisions about participation should be made on an individual basis; these decisions should be based on clients' cognitive level and preparedness for events.

By far the most common idea expressed by respondents was that the decision to involve a person with DD in funereal rites was to be made individually ($N = 14$). A thesis closely related to the "individual decision" theme was that the judgment should be based primarily on either: a) the developmental level of the person and their related ability to cognitively process (often expressed as "make sense of") events; or b) the degree to which that client had been prepared for involvement on an a priori basis. Though addressed by relatively fewer respondents, a third subtheme was protecting consumers with DD from grief and loss. One respondent neatly symbolized this entire theme:

. . . Some people may benefit from viewing [the] open casket . . . assist in grief processing etc. To others—it just seems bizarre and sets them up for negative obsessions (longer/shorter attention spans etc.). Preliminary details (such as medical) are usually confusing. Some MR adults lack sophisticated concepts of time; so prolonged deaths can seem confusing.

It should be noted that, despite her concerns, this staff member also argued that grieving rites typically facilitate the adjustment of higher-functioning individuals. Others wrote more directly about developmental *level* issues:

I believe they have a right to know so they can grieve the loss—If they can understand the dying process. . . .

This [inclusion] must be handled on an individual basis by persons who know the bereaved in terms of . . . thinking patterns and skills, mode of communication and who genuinely cares for the bereaved.

Certainly included . . . but level of ability and degree of behaviors should be considered with each client and with consideration and respect given to family members.

If we interpret this last comment correctly, we suppose it to mean that a potential exists for the person with a developmental disability to be burdensome and troubling during a difficult period for other family members and that this should be part of the decision calculus regarding whether or not or to what degree the individual with DD should be included.

Theme Two: Normalization of the experience.

Several subcategories could reasonably be combined to reflect that essentially in all or nearly all cases the experiences of persons with disabilities should match the culturally mandated social norms. Subthemes included "they should know" (about the loss; $N = 7$) and the importance of choice ($N = 4$). Staff members writing these comments seemed to echo the thoughts of Wolfensberger (1972,

1983) that the test for serving clients with disabilities is to examine practices in light of culturally normative customs.

[Participate?] Yes, as anyone else would.

They should be included in the process. . . . There should never be the attitude "Oh, they don't understand anyway."

[They should be] included as much as possible. All information should be explained to the person to the best of your ability. . . . I think the person should be fully involved.

It would be nice for that person to choose their own funeral needs if they understand the process.

Theme Three: Technical aspects of dealing with death and dying.

Several of the comments reflected somewhat dispassionate statements about staff needs ($N = 3$), clients' needs (many), and specific praise of counseling ($N = 5$) and ritual ($N = 3$). Several participants emphasized the importance of "talking" or "working through" grief with staff members, professional counselors, or trusted friends. Two writers suggested that the trusted staff member would be the *best* person to counsel the person with DD through the death experience.

I think that the staff person they like and trust the most should help them through the process.

They have feelings to express just like any other person . . . [also theme two]

Three respondents expressed particular praise for the healing effects of funereal rites:

As an agency we do everything we can to educate families about the importance of [the individual with DD] attending the funeral/memorials to help grieve their loss.

DISCUSSION

We estimate that, each year, as many as 9 in 10 residential staffers may confront the bereavement of one of their clients (86%), though the possibility exists that, despite instructions to the contrary, surveys were differentially returned from residential placements where bereavement was suffered, thus producing an overestimate of the parameter. In other words, the sample may not have been representative in regard to the annual proportion of facilities in which an individual client suffers the death of someone near to them. Nonetheless, it is probably safe to assume that the great majority of residential staffers will eventually experience the need to counsel bereaved clients. This observation is particularly salient if persons with disabilities become close with one another

because some indication exists that life expectancies are shorter enough in persons with disabilities that, even controlling for cohort variability, their death rate is significantly higher (McGuigan, Hollins, & Attard, 1995).

Attitude data, both in terms of the qualitative and quantitative information, suggested mixed results in terms of what caregivers view as important. Clear majorities endorsed such fundamental rights and needs as established in the literature, needs such as attending the funeral, coaching individuals on what will happen during rites, and informing clients about a loved one's serious illness. Several respondents penned comments revealing that they understand the importance of participation in culturally sanctioned events surrounding the death of a loved one. In light of currently understood best practices, this can perhaps be portrayed as the good news.

A sense of overprotectiveness, perhaps even infantilization, however, also emerged from these data. In a legal sense, this attitude could almost be described as prior restraint. We might characterize this reasoning as follows: persons with DD need to be protected from events surrounding bereavement. In addition, predictions about whether or not an individual will be hurt or confused as a result of participation can reliably be made by an outside individual, generally on the basis of developmental level, personal characteristics, or whether the individual with disabilities has received training or other preparation.

Wolfensberger (1972, 1983) argued that persons with disabilities enjoy the absolute right to participate in all culturally sanctioned activities. In the case of persons whose disabilities most affect their life, it is perhaps useful to integrate two somewhat competing notions. First, since it cannot be absolutely known what a person understands, it behooves programmers and family members to assume that the individual understands what is going on and that the rites surrounding death will facilitate healthy grieving. Second, because of cognitive developmental-based differences in the understanding of death and its attendant beliefs and rituals, those working with persons with cognitive disabilities should take a proactive stance and provide education about death and dying on a regular basis. These experiences should be undertaken frequently; it is possible that in gearing up to provide these services, family members and staff persons will gain insights into their own attitudes toward grieving and how it may best be managed. These data run parallel to those reported by Thornton and Zanich (2002). Specifically, to the extent that caregivers support the need of clients to participate in the grief process, it can be concluded that the grief of persons with DD is enfranchised. However, the overprotectiveness expressed by some caregivers and a priori notions that such individuals cannot understand death and dying may serve to disenfranchise persons with DD living in residential facilities.

A clear weakness of the present study was a lack of a theoretical framework for posing and answering fundamental questions about grieving in persons with DD. We view Doka's model of disenfranchised grief as an extremely useful rubric for organizing future investigations of the process as experienced by persons

with developmental disabilities. Specifically, questions can be posed under Doka's rubric about the degree to which persons with DD are seen as not needing to grieve because of assumed shortcomings in their understanding of issues surrounding death and the degree to which such perceptions on the part of care workers and family members limits the assistance that persons with DD receive as they grieve a loss.

Strictly speaking, as training is statistically independent of years' experience, it appears that some facilities provide or encourage regular death and dying training while others do not. The trend observed in the statistical analysis suggests that with about 25 more cases, the difference between "trained and untrained" staffers would have proved significant. This suggests that many staff members ultimately receive training. Given the present data, however, the most defensible assumption is that staff training on death and dying needs to occur more often than it currently does, probably a difficult proposition given turnover rates and competing professional development needs in residential service agencies.

Despite the relatively small numbers, it is obvious that the same type of mood and behavioral disturbances that affect persons without disabilities exist in a plurality of persons with mental disabilities. However, since no directly comparable data set exists for individuals without disabilities, the argument cannot be made that persons with DD suffer more or grieve less effectively than others. Nonetheless, care givers should be alerted that as many as a half of their bereaved clients will show affect disturbances for more than a month and perhaps as many as a quarter may experience sleep problems. Certainly, this issue deserves more attention from researchers and practitioners.

Interpretations based upon the present data set must be considered preliminary, due to the small numbers of responses and the regional restriction of the sample. In future studies of this type, such factors as the size and type of residential program must be included. In addition, a much larger and more nationally representative data set must be collected. Such a data set may allow for an investigation of pertinent issues not adequately addressed here. For example, it is imperative that researchers look at the statistical relationship(s) between training (both of staff members and residents), participation in rites and rituals, and adjustment. Better estimates of the degree of disabilities and related adaptive behavior difficulties than those afforded in the present investigation would likely facilitate a more precise analysis of bereavement related adjustment problems. Given a larger and more representative sample, it may be possible to pinpoint aspects of training and grief management that predict the healthiest outcomes.

It is clearly an oversight that we did not pinpoint the relationship between the individual who died and the target individual with disabilities and attempt to measure the proximity and intensity of this relationship. It is likely that the nature of the link between living individuals with disabilities and decedents may affect both participation and behavioral trauma indices (Thornton & Zanich, 2002).

Finally, we can't help but conjecture that when caregivers and residents grow close the difficulties engendered by loss may transfer to staff members as they help consumers adjust to bereavement. The possibility that the process of grief may transfer to counselors and direct-care staff members deserves the attention of researchers, as it certainly would affect the nature of training offered to residential care staff.

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