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Grief and its Complications in Individuals with Intellectual Disability

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Abstract

Bereavement and loss have significant impact on the lives of individuals with intellectual disability (ID). Although there is a growing impetus to define the symptoms of grief that predict long-term functional impairment, little is known about maladaptive grieving among individuals with ID. We examine the literature concerning the phenomenology of traumatic grief (TG) in the general population, along with what is known about the manifestations of grief in individuals with ID. We then apply modern theories of grief and grief resolution to individuals with ID in order to highlight potential areas of vulnerability in this population and to lay the groundwork for interventions that will facilitate their adaptation to loss. We provide a theoretical framework for the proposition that individuals (including children and adults) with ID are more susceptible to TG, based on an increased risk of secondary loss, barriers to communicating about the loss, and difficulty finding meaning in the loss. We conclude that individuals with ID should be considered as potential candidates for targeted bereavement interventions. Further research is required, however, in order to develop population-appropriate measurement scales for testing these hypotheses.

Keywords

grief; bereavement; intellectual disability

Early psychodynamic theories of grief suggest that only those who are capable of understanding the finality of death, and who are able to perform the arduous psychological task of withdrawing emotion from the deceased, will be capable of mourning.¹⁻⁴ Even without a cognitive understanding of death, however, it is possible to notice the absence of a loved one and to react emotionally to that loss. In his formulation of attachment theory, John Bowlby⁵⁻⁷ provided the first theoretical framework for the proposition that even young children can grieve following the loss of an attachment figure. Since then, studies have confirmed that children react with grief, sadness, and despair to the death of loved ones.⁸

Individuals with intellectual disability (ID) have long been considered incapable of grief—just as young children once were. It has been suggested that individuals with ID* do not possess either the necessary capacity to form meaningful relationships^{9,10} or the necessary

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*In this article the terms *intellectual disability* and *mental retardation* are used synonymously and refer to a heterogeneous set of recognized syndromes and idiopathic conditions, presenting with significant functional limitations in cognitive and adaptive functioning and originating before age 18.

understanding of death¹¹ to result in the experience of loss and mourning. We now know this suggestion to be false. Individuals with ID have a wide spectrum of abilities, as well as disabilities, and their psychological and emotional well-being need to be assessed relative to their life experience. Data from case studies,^{12–16} direct interviews,¹⁷ and population-based studies^{18,19} show that individuals with ID react to bereavement with emotional disturbance, including sadness, anger, and anxiety, and behavioral disturbance, including irritability and lethargy or hyperactivity. The recognition that individuals with ID are susceptible to the stress of bereavement highlights the importance of developing a paradigm to help facilitate their effective coping with grief.

We know that bereavement can be profoundly disturbing to the survivor. In the general population, grief has been shown to be a risk factor for both psychiatric^{20–25} and somatic illness.^{26,27} The afflicted person is at higher risk for suicide²⁸ and mortality in general.^{27,29,30} In particular, researchers since Freud¹ and Lindemann³¹ have recognized that some people, more than others, remain incapacitated by grief for significant amounts of time following bereavement. This pathological grief response has been referred to as complicated,³² abnormal,³³ morbid,³⁴ and unresolved.³⁵

Inherent to the concept of pathological grief is the assumption that although grief is a highly idiosyncratic reaction that encompasses a wide range of physiological and psychological responses, some ways of grieving are objectively healthier and more adaptive than others. Implied, also, is the notion that it is possible to define a “normal” grief reaction in a given population. Although a group of researchers in Britain has begun to apply the concept of pathological grief to adults with ID,^{18,18,36,37} there is as of yet no clear description of a healthy grief response in individuals with ID, and whether or how it differs from grief in other adults.

In contrast, among researchers who work with adults in the general population, there is now a growing push to identify those symptoms of grief that predict long-term functional impairment and to define pathological grief as a separate nosocomial entity, or syndrome.³⁸

In this context, bereavement experts studying grief in elderly adults have recently developed the concept of “traumatic grief” (TG), a pathological grief response that is distinct from depression or anxiety and that may be the operant risk factor for the negative health effects of bereavement.^{39–47} These studies show a compelling relationship between symptoms of TG and morbidity in the bereaved, thereby suggesting that grief reactions deserve focused and qualitative study, especially in vulnerable populations.

Against this background, Dodd and colleagues³⁶ have argued for more research aimed at accurately describing the specific symptoms of TG in individuals with ID. We agree that such a description would significantly advance our understanding of how individuals with ID experience bereavement. In addition, we maintain that it is equally important to examine how situational factors and individual characteristics mediate the ability of individuals with ID to cope with grief. At its core, the concept of pathological grief is an acknowledgment that some individuals, in some circumstances, cannot recover effectively from grief. Therefore, identifying those psychological and environmental factors that place an individual at risk would greatly assist in targeting our supportive interventions. As clinicians who work with individuals with ID, we are interested in identifying and developing interventions that will facilitate healing and adaptation to loss. We also wish to understand which individuals require no professional help to recover from grief—and may even be harmed by such intervention. Despite the proliferation of grief-counseling services, reviews of the research conducted on the efficacy of grief therapy in the general population have demonstrated equivocal results for both adults^{48–52} and children.^{52–53} A common

conclusion across these reviews, however, is that mourners who are “high-risk,”⁵⁴ including those who exhibit symptoms of “complicated”^{49,54} or “traumatic”⁵¹ grief, do actually benefit from grief therapy. Accordingly, Neimeyer⁵¹ concludes that “grief therapy is appropriately offered to mourners experiencing protracted, traumatic or complicated grief reactions,” whereas “grief therapy for normal bereavement is difficult to justify.”

Identifying TG in individuals with ID has the potential to dramatically improve the clinical care of these patients. Are individuals with ID at high risk for pathological grief? Are they therefore, as a group, good candidates for targeted grief therapy? Unfortunately, individuals with ID represent a particular challenge for study in this domain. Limitations in cognition and communication make it difficult for persons with ID to convey their thoughts and feelings to investigators, and standard grief scales^{41,55,56} rely on language and concepts that are not appropriate for use in this population. Though perhaps explaining why persons with ID have received so little attention in grief research, these difficulties do not justify continued disregard for the needs of this population.

This article addresses three central questions: Can the concept of TG be applied to individuals with ID? If so, can it explain the manifestations of grief in this population? And how can the concept of TG be used to guide the research agenda in studying grief in individuals with ID? We examine prior studies on the definition of TG and on the effects of grief in individuals with ID. Drawing from the literature, we highlight factors that may make individuals with ID vulnerable to TG. Throughout, we relate our hypotheses concerning grief in the ID population to modern theories of grief and of grief resolution in the general population. Finally, we focus on the possibilities for bereavement intervention in persons with ID and on avenues for further research.

PATHOLOGICAL GRIEF IN THE GENERAL POPULATION

According to the *Diagnostic and Statistical Manual of Mental Disorders*,⁵⁷ the only recognized complication of bereavement in the general population is depression. As noted earlier, however, the concept of pathological grief is coming to be seen as a separate diagnostic entity that is deserving of dedicated study,³⁸ with TG specifically defined as a distinct cluster of symptoms—as a syndrome—that both predicts and includes future morbidity.^{39–47} According to consensus criteria for the disorder,⁴⁵ which are summarized in the text box, TG is a stress response syndrome whose symptoms include (1) *separation distress* (for example, yearning, searching for the deceased, excessive loneliness resulting from the loss) and (2) *traumatic distress* (for example, feelings of numbness, disbelief about the loss, being stunned or dazed, having a fragmented sense of security and trust, having intrusive thoughts about the deceased).

Importantly, the work on TG emphasizes the distinction between pathological grief and other disorders, such as depression and anxiety, which are typically associated with bereavement. As the growing body of work by Prigerson and her colleagues⁴³ demonstrates, TG predicts substantial morbidity over and above depressive symptoms. For example, in one study, grief symptoms were found to predict impairments of global functioning, sleep, mood, and self-esteem 18 months after spousal loss, even after controlling for baseline levels of depression. Unlike depressive symptoms, symptoms of TG did not respond to treatment with tricyclic antidepressants or to antidepressive psychotherapy.^{58,59} Furthermore, TG is a surprisingly common complication of bereavement: across studies, the incidence of TG was consistently found to be about 20%.⁶⁰

CAN THE CONCEPT OF TRAUMATIC GRIEF BE APPLIED TO INDIVIDUALS WITH INTELLECTUAL DISABILITY?

To date, very little consideration has been given to the distinction between normal and pathological grief in individuals with ID. One culprit may be “diagnostic overshadowing”: the tendency to ascribe any emotional or behavioral difficulty to the disability itself, and therefore to minimize the importance of emotional state or situational change.⁶¹ Indeed, studies indicate that caregivers underestimate the impact of grief on individuals with ID,^{62,63} even when the affected individuals are able to express their sadness and anguish.³⁶ Furthermore, the task of studying TG, which is defined in terms of complex and nuanced emotions, is particularly daunting in individuals with limitations in cognition and communication. For example, screening questionnaires, which ask respondents to rate statements such as “I feel that it is unfair that I should live when this person died”⁴¹ are not useful in persons with cognitive impairment.

Recent work on TG overcomes this limitation by focusing on measurable outcomes, such as the ability to perform everyday tasks, which can be recorded by an outside observer. In practical terms, the accumulated work on TG suggests that independent of depression and anxiety, grief affects one in five adults in ways that produce long-term impairment.^{40–47} These findings suggest that even in the absence of a clear definition of “normal grief” for individuals with ID, further research is required and appropriate in order to determine when and how their daily functioning is impaired by pathological grief responses.

THE EFFECTS OF BEREAVEMENT ON PEOPLE WITH INTELLECTUAL DISABILITY

So far, much of the work concerning reactions to grief among individuals with ID consists of descriptive case reports.³⁶ From these, it is clear that, as in the general population, grief can precipitate various psychiatric disorders, such as depression,^{12–14} mania,¹⁵ and psychosis.¹⁶ Even in the absence of overt psychopathology, participants in these studies described grief as disruptive and disturbing. Using structured direct interviews of adults with moderate to severe ID, Harper and Wadsworth¹⁷ found that over half of the respondents reported at least one death that was very disruptive to their lives; more than a year after the deaths, the majority of these respondents were still suffering from feelings of loneliness, anxiety, and sadness, as well as from behavior problems.

It is against this background that the group of researchers in Britain have been studying TG in adults with ID.^{18,19,36,37} Absent a reliable description of “normal” grief in individuals with ID, they, too, based their initial studies on observations of psychiatric illness and behavioral change.

In the first of these studies, Hollins & Esterguyzen¹⁸ studied 50 bereaved adults with ID, matched for age and disability with 50 controls, using the Aberrant Behaviour Checklist (ABC)⁶⁴ and the Psychopathology Instrument for Mentally Retarded Adults (PIMRA).⁶⁵ The bereaved group was significantly more irritable, lethargic, and hyperactive, and had significantly more inappropriate speech. Within the bereaved group, there were also significantly more cases of depression and anxiety disorders than in the control group. This study is important because it was the first study of bereavement in ID to use a control group and to quantitatively compare indices of behavioral disturbance.

Approximately five years after parental bereavement, a follow-up study was conducted with the same bereaved group.¹⁹ Whereas in the initial study 21 participants met PIMRA criteria for psychopathology (by scoring “case present” on at least one of the subscales for affective,

anxiety, or adjustment disorder), at follow-up 18 of these participants no longer scored. This finding was interpreted to suggest a reduction in affective disorder and anxiety disorder symptoms, as is consistent with the “normal” pattern of recovery from grief. Other individuals, however—who had not scored as cases in the initial study—did score at follow-up. This finding was interpreted as possible evidence of a “delayed grief reaction” and identified as pathological grief, according to the the *International Classification of Diseases*,⁶⁶ which confines “normal” grief to that which occurs within one month of the death and lasts no more than six months.

Together, these British studies are an important first step in the qualitative study of grief in individuals with ID. It is premature to conclude, however (as these authors do in a later article),³⁷ that these studies provide “growing evidence that many people with ID experience atypical and prolonged grief following the death of a family member or close friend.” Delayed grief is one possible explanation for the appearance of new cases at follow-up, but there are important limitations to this conclusion—namely, the failure to follow-up with controls and to take possible intervening life events (even another death) into account. Furthermore, although DSM-IV also specifies a time course for “normal” grief, the more recent work on TG emphasizes the qualitative characteristics of pathological grief rather than its duration or time of onset.

Much more convincing (and encouraging) is a randomized, controlled trial performed by the same British group comparing two community-based interventions for bereavement in adults with ID.³⁷ The study’s express aim was to find an effective way to improve mental health and behavioral outcomes following bereavement. Forty-seven adults with ID who had experienced a significant bereavement were randomized to receive either 15 sessions with a volunteer bereavement counselor or bereavement-specific support from their usual caregivers. The latter option was not a success: support was often haphazard or incomplete; it was also frequently discontinued for fear of upsetting the patient (one reason why individuals with ID are often excluded from mourning rituals in the first place). In contrast, the counseling intervention resulted in dramatic improvement in a majority of cases, both in terms of objective measures—the ABC and the Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD)—and subjective reports. In general, participants were pleased with the opportunity to talk with someone one-on-one about their grief, and experienced overall improved functional outcomes. Although this study did not attempt to qualify the type of grief experienced by the participants, it supports the notion that people with ID are negatively affected by grief for a sustained period following bereavement. The study also highlights both the tendency of carers to “shield” or “protect” individuals with ID from talking about grief, and the beneficial effect of breaking this silence. Finally, the approach was progressive in its focus on functional and quality-of-life outcomes, rather than on indices of depression or anxiety.

DO INDIVIDUALS WITH INTELLECTUAL DISABILITY REPRESENT A GROUP OF HIGH-RISK MOURNERS?

To date, research in the general population has discredited the notion that routine intervention should be provided simply because an individual has experienced a bereavement.^{48–53} Estimates of treatment-induced deterioration by Neimeyer⁵¹ revealed that 38% of recipients of grief counseling would theoretically have fared better if simply left alone. According to Parkes,⁶⁷ grief counseling is warranted only for “the minority of people who are faced with extraordinary stress, who are especially vulnerable and/or see themselves as lacking support.” These high-risk mourners include individuals who, for whatever reason, are suffering from unremitting or increasing levels of distress; in particular, Jacobs and Prigerson⁶⁸ have offered a review of interventions that show promise in treating individuals

who meet criteria for TG. As Schut and colleagues⁵⁴ concluded: “the more complicated the grief process appears to be, the better the chances of interventions leading to positive results.”

Do individuals with ID as a whole represent a group of high-risk mourners? Dowling and colleagues³⁷ seem to suggest that complicated grief is near universal in this population and that routine bereavement counseling is therefore warranted. Although we believe this conclusion to be premature, we recognize both that bereaved individuals with ID have typically been *undertreated* and that persons with ID, by virtue of their cognitive and functional limitations, may be placed under “extraordinary stress” in times of mourning. Well-designed treatment programs have the potential to dramatically improve psychological and behavioral outcomes for bereaved persons with ID. More research in this area is obviously necessary: in order to predict which, if any, persons with ID are susceptible to TG, we need to understand how individuals with ID compare to others in terms of those factors—emotional, situational, and cognitive—that influence coping with grief. It is to these issues that we now turn.

ARE INDIVIDUALS WITH INTELLECTUAL DISABILITY PARTICULARLY VULNERABLE TO COMPLICATED GRIEF?

We hypothesize that, because of several risk factors, individuals with ID may have more difficulty than the general population in coping with grief. In the following sections, we will consider three areas identified by the literature as important for the recovery from grief, and in which we believe individuals with ID exhibit significant vulnerabilities: (1) how individuals (adults as well as children) with ID may be affected by secondary loss following the death of a loved one; (2) the problems that individuals with ID may have with communicating effectively about the loss; and (3) the ways in which cognitive limitations may affect their search for meaning in loss. Since myriad factors potentially affect the stress associated with any given loss, we have chosen to focus on some to the exclusion of others, such as the characteristics of the death itself (i.e., whether the death was sudden vs. anticipated, violent vs. nonviolent, or age appropriate).

Secondary Loss and Coping with Grief

When a loved one dies, the loss is not only of the person himself or herself, but of the way of life that that person helped to build. Recent work in grief theory recognizes the multiplicity of losses inherent to the experience of losing a loved one, and seeks to establish a framework for coping with both the primary loss and the secondary losses that can range from loss of a weekly baseball game to loss of one’s home.^{69–71} Adults and children, who play different roles within the family structure, tend to experience different types of secondary loss and require different coping strategies. Both are relevant to understanding the compounded stress experienced by individuals with ID following a death.

Adults—For normative adults, even though the primary loss is unchangeable, many secondary losses can be corrected or mitigated through so-called *restoration-oriented* coping;⁶⁹ for example, a widow can go back to work in order to regain the financial security lost by the death of her husband. During the course of recovery from grief, normative adults typically evaluate not only the personal harm done by the loss, but also the effectiveness of the coping strategies that they been used.⁷⁰ Thus there may actually be positive consequences of bereavement, such as pride in the accomplishment of new tasks or in the assumption of a new role.

In contrast, adults with ID often are not capable of taking an active role in the restoration of the family following a death. To an individual with ID who cannot live alone or support himself financially, secondary losses may seem as immutable and final as death itself. Since individuals with ID are rarely called upon to assume the responsibilities of lost family members, they do not have agency in helping themselves or their families. More likely, their care is a responsibility that needs to be shifted from the deceased person to someone else. Rather than experiencing positive self-growth, individuals with ID may view themselves as a burden or simply fear that they will not be taken care of.

Children—Children (and often adults) with ID, like other children facing bereavement, depend on their parents for food, shelter, and daily care. For both groups, parental death is likely to be followed by a series of disruptive life events—including changes in domestic routines, primary caregivers, homes, or schools—that can be experienced as secondary losses. Significant changes can make it difficult for children to cope: in families bereaved by parental or sibling suicide, the number of life events experienced by the bereaved child (both pre-and post-loss) correlates with the child's psychiatric symptoms.⁷² Similarly, people with ID experience psychological and behavioral disturbance in reaction to significant life events.^{73–76}

In children, the literature suggests that the best predictors of good outcome are those that shield against secondary loss: a good relationship with a surviving parent who is competent in parenting bereaved children^{77–80} and a stable family environment promoted by strong family organization, cohesion, communication, and role differentiation.^{8,81} It seems reasonable to infer that maintaining stability in the home is critical for the well-being of bereaved individuals with ID.

Unfortunately, because they have special care needs, and because they may remain dependent on family members well into adulthood, young individuals with ID are at highest risk for unstable family situations and multiple, stressful life events following the death of a parent. And as their family members age, the probability of losing both parents to death only increases. Loss of the last surviving caregiver may result in loss of home and in placement in residential care or an unfamiliar group home. Individuals who are forced to move into emergency accommodation often end up moving as many as four or five times in the year following a major bereavement.⁸²

The literature regarding non-ID children suggests that children who had a highly involved relationship with the deceased parent but low involvement with the surviving parent are at high risk for behavioral or psychiatric disturbance.^{83–85} Many individuals with ID have two parents who are deeply involved in their care; however, because of their special needs, one caregiver may well have played an indispensable role. And because many individuals with ID have profound difficulty with communication, especially verbal communication, their lifetime primary caregiver may be the only person to whom they can effectively express their needs or desires. That same parent may have also amassed decades worth of medical knowledge and be the only family member capable of navigating the system of state and federal supports. Loss of this primary caregiver can therefore be devastating.

Communicating About Loss

Given the tendency for caregivers to minimize the effects of grief in individuals with ID, as well as the communication difficulties inherent in many types of ID, people with ID may have few or no opportunities to talk with friends or family members about their loss. The question of whether talking about a death facilitates coping with grief is an important one. It has implications for how health care professionals should educate the caregivers of

individuals with ID, and raises questions concerning the potential efficacy of psychotherapy-based bereavement intervention in this population.

Bereaved individuals with ID turn to family members for emotional support and for help with understanding the events surrounding the death. Both types of communication—emotional and informational—appear to help typically developing children cope with the death of a parent.⁸⁶ For example, it is common for children to feel guilty because they believe themselves responsible for a parent's death, or to be hurt by a terminally ill parent whose inability to play is interpreted as withdrawal of love.^{87–89} It is reasonable to infer that children with ID, like other children, should be provided comprehensible, age- and intellect-appropriate information about illness and death.^{77,90,91} Similarly, children with ID would also benefit if families were more open in communicating about their feelings following a loss.^{92,93}

Unfortunately, many parents find it difficult to communicate with children about death, especially when they themselves are dealing with the loss a spouse. There is abundant evidence for breakdowns in both factual/informational^{77,94} and affective/emotional^{95,96} communication surrounding the death of a parent, even when the surviving parent reports that he or she is aware of the importance of communication.⁹⁴ The situation is likely to be even worse among families of individuals with ID—and especially with disabilities such as Down's syndrome (DS), who characteristically show uniquely exaggerated vulnerabilities to separation and loss. There is still a prevailing notion that it is better to shield individuals with ID from information that “might upset them” or have undesirable emotional or behavioral consequences. As Dowling and colleagues³⁷ showed, even caregivers who were given training and a specific mandate to focus on bereavement issues had trouble talking about grief to their family members with ID. Although many individuals with ID, including persons with DS, have specific deficits in verbal communication, studies show that, when asked, these individuals are able to communicate about their feelings and concerns.^{17,36} Consequently, when considering the potential utility of professional bereavement intervention, we need to consider the likely dearth of communication opportunities in the home.

The Search for Meaning in Loss

Human beings, perhaps uniquely, respond to bereavement at a *cognitive* level. We must struggle intellectually to “relearn the self” and “relearn the world”⁹⁷ in the absence of a loved one who helped to structure our lives and life goals, and to recreate a “meaningful narrative”⁹⁸ that explains or at least incorporates the transitions that follow loss. For example, an adult child whose major preoccupation was ensuring good quality care for her mother must, after her mother dies, reconstruct a characterization of herself beyond the role of caretaker.

Some investigators performing qualitative research on grieving adults^{51,98–105} have emphasized the importance of “meaning making”⁸⁶ as a strategy for coping with grief. Neimeyer¹⁰² has gone so far as to argue that “meaning-reconstruction in response to a loss is the central process in grieving.” From this point of view, many of the symptoms of TG—disbelief, meaninglessness, inability to project into a valued future, loss of identity, and shattered worldview—are nothing more than manifestations of an individual's unsuccessful struggle to make existential sense of a loss.⁹⁸

This emphasis on “making sense” of a loss raises questions concerning the extent to which, and in what way, intellectual ability affects an individual's ability to cope with grief. As we have seen, individuals with ID were, until recently, considered to be spared from the pain of grief because they did not have the ability to understand what had happened. Recent

evidence does indicate that some mourners never engage in any search for meaning, and suggests that they do just as well as, or better than, their counterparts.¹⁰⁶ In that same study, however, the participants who fared the worst were those who searched for meaning but were unable to find it.¹⁰⁶ To date, no one has investigated the relationship between intellectual ability and success at the “meaning-making” level. Are individuals with ID more likely than other bereaved to accept death without needing to search for meaning? Or are they, instead, more likely to undertake an unsuccessful search? These unanswered questions are further complicated by the significant heterogeneity and wide range of abilities (as well as disabilities) among individuals with ID. Nevertheless, several studies suggest that most adults undertake an explicit, cognitive search for meaning following the loss of a loved one^{106,107} and that successful integration of the loss into a broader meaning structure helps recovery.^{108,109} The inability or impaired ability of individuals with ID to cognitively create meaning in loss is another potential source of vulnerability to pathological grief.

Davis and colleagues¹⁰⁶ have made a novel distinction between “making sense” of loss and “finding benefit” from a loss. Whereas the former refers to fitting the loss into a view of a just world, the latter refers to discovering a sense of value and purpose in one’s own life following the death. The authors found that in the long-term, only those mourners able to develop a new, stronger sense of self had improved outcomes.¹¹⁰ Thus the ability to “find benefit” seems intimately tied to the ability to mitigate secondary loss by revising one’s goals and priorities in response to death, and to grow and change following a loss—for example, by reevaluating how to approach other relationships.¹⁰⁶ Unfortunately, these tasks may be especially challenging for individuals with ID. Not only is this type of complex reevaluation difficult for persons of limited cognitive flexibility, but many individuals with ID occupy a dependent position within the family structure and may therefore be denied opportunities for growth and change.

Finally, it is worth noting that in the study of Davis and colleagues,¹⁰⁶ the ability to find benefit from a loss was reported not to be affected by contextual details of the death (e.g., age of the deceased), but *was* affected by the personality of the mourner. Those who were more pessimistic before the death were significantly less likely to find any silver lining (or “benefit”) in the experience of loss. This finding indicates that the psychological characteristics of the bereaved play an important role in shaping the grief response. Though we do not know whether individuals with ID with specified syndromes tend to be more or less optimistic than the general population, we do know that individuals with DS experience higher rates of affective and anxiety disorders than the general population¹¹¹ and may lack the psychological resilience necessary to derive meaning—especially any beneficial meaning—from loss.

CLINICAL IMPLICATIONS

One of our goals was to determine whether routine bereavement intervention is justified in individuals with ID. According to the existing literature, this type of outreach would be warranted only if individuals with ID demonstrated significantly increased risk for complicated grief. Based on the theoretical framework presented above, however, individuals with ID are much more likely, for various reasons, to need enhanced professional support in order to cope with grief. Furthermore, in contrast to the general population—where there has been a proliferation of bereavement services—evidence in persons with ID^{61–63} points to a dearth of bereavement interventions for this population and to the continuing occurrence of unrecognized grief. We therefore agree with Hollins and Sinaison⁶¹ that we stand to gain from increased use of psychotherapy for the treatment for individuals with ID (both adult and children) who experience emotional problems, whether related to grief or not. There has been increasing evidence for the successful use of

psychotherapy in individuals with ID,^{37,112–114} particularly in Britain, where the Royal College of Psychiatrists¹¹⁵ has advocated—within a national mental health policy framework—a nationwide provision of psychological therapies for people with ID. More generally, the direction of British policy is to provide care to people with ID as part of the existing mainstream services, with specialist ID services providing any additional training and support that may be necessary.¹¹⁶

Recent reviews have advocated more rigorous descriptions of the theoretical models that underpin bereavement-intervention programs.⁴⁹ Neimeyer⁵¹ further speculated that a “possible reason for the weak showing of grief counseling is that it rarely draws on the best available theories regarding the nature of bereavement and its facilitation.” Thus, the use of sound theoretical frameworks has the capacity to identify vulnerabilities in individuals with ID and consequently to shape treatment programs that can then be further refined through empirical testing. For example, on the hypothesis that individuals with ID may be affected by their lack of agency in shaping their post-loss family roles, there is support for Parkes’s suggestion¹¹⁷ that the therapist help restore those individuals’ self-confidence and engagement in life by working with them to set and achieve small goals. Likewise, realizing that individuals with ID often have little opportunity to talk about their feelings following a loss might prompt communication-focused counseling sessions such as those used in the study by Dowling and colleagues.³⁷

RESEARCH IMPLICATIONS

So far, research on grief in individuals with ID has focused mainly on determining whether, and to what extent, this population experiences grief. It is time to move toward a more nuanced conception of how persons with ID mourn and of the strategies that they can use to recover from grief. In all populations, the current challenge for bereavement researchers lies in understanding why some grievers seem to fare so well, whereas others remain stuck in misery. In working with individuals with ID, we must first learn to distinguish the former from the latter. Making this distinction will help us learn which attitudes, behaviors, and methods facilitate adaptive recovery from grief. Ultimately, then, we will be able to apply these lessons toward treating troubled mourners, by helping them access these successful strategies.

As we have seen, information gleaned from caretakers has proven to be unreliable, both because they tend to minimize the effects of grief in individuals with ID, and because they are often themselves struggling to cope with grief. In conducting research, it is consequently of central importance to communicate directly, whenever possible, with the bereaved individuals themselves. To that effect, it will be necessary to develop well-designed grief scales that rely on concepts and language appropriate for this population. Because we currently know so little about the issues facing bereaved individuals with ID, it is also advisable that study designs incorporate a mix of qualitative and quantitative elements.^{118,119} As Neimeyer and Hogan¹¹⁹ have suggested, both numbers and narrative can contribute distinctive forms of understanding about bereavement processes. In the case of individuals with ID, qualitative study based on semistructured interviews can help to identify new issues not yet included in standardized self-report measures, leading to a further refinement of the quantitative tools currently in use.

The research by Prigerson and her colleagues^{40–47} into the phenomenon of TG strongly suggests that complicated grief is an entity distinct from other mental disorders. It is consequently important to interrogate subjects about the experience of grief itself (e.g., feelings of yearning for the deceased) rather than focusing exclusively on the symptoms of grief-related disorders, such as depression. Moreover, given the operational definition of

pathological grief as a pattern of mourning that produces long-term functional impairment,⁴¹ bereavement investigators working with individuals with ID should take seriously any deviation from functional baseline. It would be incorrect to assume, however, that individuals with ID are incapable of experiencing positive growth and change following the death of a loved one; research designs should therefore allow for the identification and measurement of positive outcomes.

Research designs also need to take into account the diversity of conditions that commonly produce below-average intellectual and adaptive functioning. ID is not in itself a disorder or a diagnosis. The study of how persons with ID cope with grief has been confused by the use of heterogeneous study populations, including individuals with varying levels of intellectual impairment and varying medical diagnoses.^{18,19,120} The manifestations of genetic syndromes include a “behavioral phenotype,”¹²¹ the “characteristic pattern of motor, cognitive, linguistic and social abnormalities which is consistently associated with a biological disorder.”¹²² Therefore, we recommend that researchers define groups of individuals whose genetic makeup may confer particular psychological strengths and vulnerabilities, and who may therefore have different strategies for coping with grief. For example, population studies have shown that individuals with DS are predisposed to depression and Alzheimer’s dementia,^{123–125} but may be protected from schizophrenia.¹²⁵ Compared to peers with ID of other etiologies, individuals with DS were found to have lower rates of conduct disorder or personality disorder¹²⁵ and lower rates of maladaptive behavior, including aggression and self-injury.¹²⁶ It is reasonable to infer that such different characteristics may well lead, in turn, to different and even distinctive patterns of grieving—not only in DS, but in all disorders that result in ID.

Finally, it is important for researchers to keep in mind that even with the group of persons with a particular form of ID, manifestations of grief are going to vary from individual to individual. That is, we should expect not only that an individual with autism might manifest grief quite differently from an individual with DS, but that different persons with DS are individual people who will manifest grief in different ways from one another, in accordance with their particular abilities, disabilities, and dimensions of personality. With that in mind, we encourage bereavement researchers to continue to incorporate current theories about grief in the general population, into their work on ID. As Meyers¹²⁷ notes in reference to responses to death, individuals with ID, “as in most other aspects of their lives, ... are more like everyone else than they are different.” Although individuals with ID may manifest grief idiosyncratically, there is no reason to assume that the core issues facing neurotypical mourners are not also those with which bereaved individuals with ID must struggle.

CONCLUSIONS

Grief is a “brutal gift”¹²⁸ that has the potential to devastate and disrupt, but that also may ultimately lead to positive psychological growth. In recent years, researchers have begun to define the qualitative differences between normal, healthy grieving, which may lead to such positive growth, and “traumatic” grieving, which is associated with long-term functional impairment. Unfortunately, this important work has largely excluded individuals with ID, in whom we still have only a rudimentary understanding of emotional states and suffering.

This exclusion is especially unfortunate because individuals with ID may, as a group, have more trouble than their typically developing counterparts in coping effectively with grief. In this article, we have raised the themes of secondary loss, communication, and meaning making—which, when taken together, illustrate the ways in which the shock of losing a loved one can reverberate through all domains of the bereaved person’s life. In addition to recovering from the loss *per se*, the bereaved person must work to reconstruct an updated

sense of the world and of him or herself in it, without the person whom they have lost. Based on our review of the current bereavement literature and on our understanding of the psychological, behavioral, and functional characteristics of individuals with ID, it seems likely that this task will pose a notable challenge to bereaved individuals with ID, especially in view of our currently inadequate understanding of how best to support them.

We have sought to highlight potential areas of vulnerability in this population of bereaved individuals with ID in order to lay the groundwork for interventions that will facilitate their adaptation to loss. We believe that with their increased susceptibility to secondary loss, barriers to communicating about the loss, and difficulty in finding meaning in the loss, individuals with ID are candidates for targeted bereavement interventions. Although at this stage we can do no more than speculate about the vulnerability of individuals with ID to TG, we believe that the formulation of such hypotheses, even at the most abstract or general level, represents a necessary first step beyond the simple *observation* of grief in individuals with ID—and toward *investigating* the elements that influence their responses to grief. There is an urgent need to develop suitable measures that will enable the objective study of grief and its complications. We hope that, over time, these and other suggestions will be incorporated into systematic studies of bereavement in this highly vulnerable population.

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Consensus Criteria for Traumatic Grief

Criterion A

1. Person has experienced the death of a significant other
2. Response involves three of the four symptoms below, experienced at least occasionally:
 - a. Intrusive thoughts about the deceased
 - b. Yearning for the deceased
 - c. Searching for the deceased
 - d. Loneliness as a result of the death

Criterion B

In response to the death, four of the eight following symptoms are mostly true:

1. Purposelessness or feelings of futility about the future
2. Subjective sense of numbness, detachment, or absence of emotional responsiveness
3. Difficulty acknowledging the death (e.g., disbelief)
4. Feeling that life is empty or meaningless
5. Feeling that part of oneself has died
6. Shattered world view (e.g., lost sense of security, trust, control)
7. Assumes symptoms or harmful behaviors of, or related to, the deceased person
8. Excessive irritability, bitterness, or anger related to the death

Criterion C

Duration of disturbance is at least two months

Criterion D

The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning

Source: Prigerson (1999).⁴⁵