Perceptions of Death and Management of Grief in People with Intellectual Disability

Article *in* Journal of Policy and Practice in Intellectual Disabilities · June 2006

DOI: 10.1111/j.1741-1130.2006.00060.x

4 authors, including:

Rianne Meeusen
Geestelijke Gezondheidszorg Eindhoven en De Kempen
2 PUBLICATIONS **10** CITATIONS
SEE PROFILE

Marian Maaskant
Marian Maaskant - Research & Advice
62 PUBLICATIONS **1,421** CITATIONS
SEE PROFILE

Journal of Policy and Practice in Intellectual Disabilities
Volume 3 Number 2 pp 95–104 June 2006

Perceptions of Death and Management of Grief in People with Intellectual Disability

Rianne Meeusen-van de Kerkhof*, Hanneke van Bommel†, Werner van de Wouw‡, and Marian Maaskant§
*Meare, Eindhoven; †Severinus, Veldhoven; ‡Máxima Medisch Centrum, Veldhoven; and §Pepijn en Paulus' at Echt, Echt and the Department of Health Care Studies, Governor Kremers Center, University of Maastricht, Maastricht, the Netherlands

Abstract The authors examine the way in which people with intellectual disability (ID) handle death and mourning, and note that the way in which death and bereavement are being experienced depends – among other things – upon the intellectual and socio-emotional age of the individual. The authors used the theories formulated by Piaget (cognitive development), Došen (socio-emotional development), Timmers-Huigens (strategies of ordering experience), and Fowler (stages of faith) to frame an explanation of how people with ID perceive and experience death. This ranges from hardly any understanding (among persons with profound ID) to a clear realization (among persons with mild ID) of death. Within this framework, the authors offer suggestions and tools for counselors that can be used to help people with ID to manage grief, contingent on their degree of emotional-cognitive-social development (e.g., offering closeness and physical contact, using specific rituals, making use of stories and photographs, and allowing participation in farewell rituals).

Keywords: experience with death, mourning, training

INTRODUCTION

In recent years, the taboos surrounding death and bereavement have been decreasing so that we can at last speak of an unmistakable change in our thinking about these subjects. Dying and mourning are increasingly considered as processes inextricably connected with life, and we now discuss them in an open manner. This new approach to death and bereavement has also had an effect on the care for people with intellectual disability (ID). When a member of the family, a friend, or companion dies, the intent is to give people with ID the best possible counseling and involve them in what happens. The specific ways of involvement depend upon their capabilities and upon what they, within the range of these capabilities, personally desire. Unfortunately, experiences of disease and death are still sometimes completely kept from their lives (Blackman, 2003; Harper & Wadsworth, 1993; Kauffman, 1994). This is done advisedly, often with the best of intentions and for any number of reasons, and spurred by the underlying thought that "they wouldn't understand it anyway" or that "they shouldn't be unnecessarily confronted with grief."

Practice teaches us that for people with ID, the death of a loved one has the same emotional consequences as for any other person. If, on the other hand, people with ID are shielded from such an experience, their noninvolvement may have consequences of the same or of an even higher order. They will notice anyway that something is wrong, and that the atmosphere around them and the pattern of their lives have changed or are changing. They will start missing the deceased just because they no longer see him.[1] If subsequently they are given little opportunity to express grief and bereavement, they may develop psychological complaints, including continuous exhaustion or depression.

To be able to mourn effectively and give adequate room to their bereavement, it is important that people with ID be involved in the passing away of a loved one. They must be given the chance to say goodbye in the proper manner and to mourn in their own way. We should bear in mind that people with ID have the capacity to and do grieve and have comparable reactions to other people (Blackman, 2003; Bornell-Pascual et al., 1999; Dodd et al., 2005; Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997; Kauffman, 1994; Van Keersop & Van de Kerkhof, 1994). However, grief may find a different expression or reveal itself at a different moment than might be the case for people without ID (Bornell-Pascual et al., 1999; Van Keersop & Van de Kerkhof, 1994). Thus, family and counselors[2] of people with ID should be well acquainted with the various ways in which death can be experienced and understood. Only then will they be able to offer

Received December 30, 2004; accepted December 10, 2005
Correspondence: R. Meeusen-van de Kerkhof, Meare, PO Box 90052, NL-5600 PE Eindhoven, the Netherlands. Tel: +31 40 264 9292; Fax: +31 40 264 9166; E-mail: r.meeusen@meare.nl

[1]"She" may be read instead of "he" as the case requires.
[2]To improve readability, the expression "family and/or direct carers/counselors" will subsequently be abbreviated to "counselors."

valuable counseling and prevent overlooking recent loss and expressions of grief (Blackman, 2003; Dodd et al., 2005; Kauffman, 1994).

The emphasis of this article is on the way in which people at different levels of ID perceive and experience death. Given what we have observed, we offer suggestions for some processes in which counselors can be helpful in trying to manage grief in people with ID. First, we describe functional levels of intellect and link them to socio-emotional development in terms of the understanding of concepts related to death and dying. Second, we describe the perceptions and experiences of death related to these levels of development and provide advice for counselors working in the area of bereavement and death counseling.

INTELLECTUAL AND SOCIO-EMOTIONAL DEVELOPMENT

The way in which death and bereavement are experienced depends – among other things – upon the intellectual and socio-emotional age of the person (Klass et al., 1996). To be able to counsel another human being requires knowledge of the level at which he or she is used to functioning, of the various levels of development, and of the aspects that play a part when a person is coping with death and bereavement.

It is not uncommon, for example, for people with ID, after the death of a co-resident or family member has been announced, to show only a fleeting reaction, and then to continue by asking if coffee will be served on time. It is therefore advisable for a counselor to know about the reactions described.

When counselors have acquired more knowledge about these levels of development and about the appropriate behavioral patterns and reactions, they will be in a better position to understand people with ID and to lend them the helping hand they need.

The arguments pointed out here are doubly important, because the levels of development in people with ID tend to vary widely. In fact, there are often considerable differences between their intellectual and their socio-emotional ages, the latter factor functioning at a lower level (Došen, 2005a). This discrepancy between levels of development is known to give rise to significant psychological and behavioral problems (Došen, 2005a; 2005b).

In the discussion of different levels of development, we can assume intellectual development as a point of departure. From here, it may be possible to establish connections with other levels of development. The intellectual age is indeed not the sole determinant of a person's functional abilities. In this respect, we emphasize the socio-emotional development and the strategies of ordering experience, as well as how the stages of faith impact upon the understanding of the world in general and experiencing death in particular. In doing so, we shall avail ourselves of the theories formulated by Piaget (cognitive development – Child Developmental Institute, 2005; Piaget, 1954), Došen (socio-emotional development – Došen, 2005b), Timmers-Huigens (strategies of ordering experience – Timmers-Huigens, 1998),[3] and Fowler (stages of faith – Fowler, 1981). The main definitions of select keywords germane to our discussion are explained in Figure 1.

Faith and development

Every human being tries to make sense of his experiences. This also applies to loss. The way in which this happens differs from person to person. This development consists of a number of stages, with periods of equilibrium and imbalance appearing in a fixed order. The disturbance of a certain equilibrium will occur when a crisis, such as a loss, is experienced. Everything that has so far made sense in someone's life seems now to be falling apart. Under certain circumstances, a new pattern of faith may be built up. A supportive environment and useful examples set by other people may help this process. Transitions such as those described here do not automatically coincide with a specific biologically defined maturity, a specific age or psychological stage of development. These factors, however, may help the person in question to make the transition to a following stage. The stage of faith that a person is going through has vital consequences for the manner in which he elects to deal with a crisis in his life. These consequences in turn determine the transition to a new stage in which new possibilities of faith are to be found.

Symbols and rituals

Symbols and rituals have existed since the dawn of Mankind. They are needed to express things for which we have no, or insufficient, words. The use of symbols is required at important moments in life.
A symbol is an object referring to something outside itself (as a ring may refer to fidelity). Symbols are closely related to a particular culture, region, people, or religion. Certain actions or words may also be interpreted as having a symbolic function.
If a symbol, a symbolic action, and symbolic language come together in repetitive usage, a ritual emerges.
Symbols and rituals are part of an old tradition. Nevertheless, they may develop even today. Sometimes they are linked to a particular person. Symbols and rituals offer us a framework within which to express our own experiences, simultaneously channelling the emotions and ordering the chaos these motions may evoke.
People with intellectual disability make a more intense use of (frequently personalised) symbols and rituals, not only because their powers of verbal communication are less pronounced, but because the imagination assists them more effectively in their experiences and intuitions. Imagination provides them with security and helps them to give order to complex reality. Especially in difficult situations, which may cause a high degree of emotion and insecurity, symbols and rituals may support them in finding an adequate place for, and in coming to terms with, these difficult situations. This certainly applies to situations of loss.

FIGURE 1
Definition of keywords.

How people function intellectually and socio-emotionally tells us something about their understanding of the world around them, about their processes of thought, and therefore about their concept of death as well. In dealing with this question, we should remember that adults with ID are different from children and should be treated accordingly. They have lived their lives and formed an image of their surrounding world. Everyone has had experiences that influence their future experiences. Even though people with ID no longer look upon the world as children do,

[3]Timmers-Huigens does not connect these strategies of ordering experience with any specific intellectual and/or intellectual age, because strategies of ordering experience remain in effect for the whole of a person's life. However, we have proposed characteristics of certain strategies of ordering experience when discussing specific intellectual levels and intellectual ages. We believe that this approach will help to clarify the different levels. Therefore, the connection of the two concepts "strategies of ordering experience" and "level of experience" expresses merely our own view.

TABLE 1
Classification denoting the level of intellectual disability (ID), IQ, and intellectual age

Level of ID	IQ	Intellectual age (years)
Profound	up to 20/25	0 to ±2
Severe	20/25 to 35/40	±2 to 4/5
Moderate	35/40 to 50/55	4/5 to 7/8
Mild	50/55 to 70	7/8 to ±12

they often may function at a comparable level of thought and conceptualization. We have said before that the kind of grief reaction depends upon certain levels of development. The levels of ID (classification following DSM-IV-TR; APA, 2000) are reflected in Table 1. It is coupled to a specific intellectual age. We are talking here about a global classification which has no absolute limits and which is based upon the arrangement according to levels of development used by Piaget (1954) and Došen (2005b).

THE EXPERIENCE OF DEATH RELATED TO THE LEVEL OF DEVELOPMENT

In this article, we attempt to define how death is perceived and experienced, including corresponding perceptions of grief and bereavement, drawing from both sources in the literature and our professional experiences. We emphasize that the stages we use are global and have no absolute limits. Subsequently, we indicate the kind of counseling that seems necessary, pointing out in which way this may be administered. In Tables 2–5 we offer a brief description of each level of ID, indicating the nature of the experiences and advisable means of counseling.

Profound Intellectual Disability (Intellectual Age 0 to ±2 Years)

Experience To people with profound ID, the only things that exist are those that can be seen, smelled, felt, and heard. Anything outside this realm of seeing, smelling, and so on ceases to exist. They are not yet able to make a distinction between their own body (the self) and its surroundings. There is, in other words, no conscious understanding of life. Neither is there any conscious understanding of death. The concept is based on sensual impressions and experiences undergone through their own body (investigation of own body, physical contact with others, with objects), as well as through the use of senses (Timmers-Huigens, 1998). In most cases, people with profound ID also have serious sensory and motor limitations. Other limitations have been diagnosed in communication and the ability to manage things independently.

It is important to know that the complete process of bonding develops in the phase of socio-emotional development. This process may be seen to start at the intellectual age of about 6 months (Došen, 2005b). Before this time, it is impossible to record any clear reaction to the death of a person. Bonding starts in children aged between 6 months and 2 years. Consequently, people with profound ID recognize familiar people (close family, regular counselors), and may be closely attached to these people. If a loved one dies, they show no reaction by crying or mourning in any other way. They do show reactions, however, that take the form of looking for the deceased person, of putting up resistance, or of aggressive behavior (Dodd et al., 2005; Harper & Wadswoth, 1993; Mönks & Knoers, 1983; Van Keersop & Van de Kerkhof, 1994). There is a tendency in people with profound ID to sense that something is wrong from the reactions of others, the change in atmosphere pervading the house, or the fact that someone is in bed all the time.

As communication is limited and in most cases nonverbal, people with profound ID are unable to express their emotions in words (Mevissen, 1999). They communicate their feelings of bereavement by way of behavior. Those around them should take care to be receptive for any pertinent signals. At this level of faith, corresponding to this level of intellectual development, the quality of confidence in general evolves from the fundamental confidence, which these persons build up with regard to the other people. A loss or similar event may threaten this maturation process. For those with profound ID, the disposition that is finally formed with regard to the world around them emerges from a subconscious level.

Counseling People with profound ID do not form an immediate awareness of the fact that someone has died. The loss makes itself felt in the course of time, sometimes only after months or years have passed. Counseling, then, should not aim to instill the person with an understanding of what dying means. To involve a person in the process of someone's dying is to try and make that person experience the changed atmosphere and feel the general change as distinctly as possible. This can be done, for example, by moving the dead person (if he died at home) in his bed to the living room. It is important for people with profound ID to be able to establish a direct contact with the deceased person, to be able to form a concrete image of him and to touch him, preferably in a familiar environment. In this way, people with profound ID have the chance to experience that the person in question is no longer alive, and that he becomes cold and is therefore not simply sleeping. An additional way to make them understand that somebody they knew is never going to come back is to leave that person's usual place empty for a while.

Reserving a quiet time for the moment of saying goodbye is another important way to allow everyone to live through the experience in their own way. People with ID are capable of treating the issue in a perfectly natural manner. Those who prefer to follow the process from a distance tend to make this desire known readily enough. The experience of death originates in the contin-

ued absence of the loved one, which may cause feelings of insecurity. To people with ID, the loss expresses itself as a breach of fixed patterns – for example, if a member of the family who used to visit at regular times suddenly fails to appear. A visible change of behavior may result, and the people with ID may start following the counselor around or not want to be left alone, they react restively and sometimes even show a tendency to inflict pain on themselves.

In most cases, it is only later that grief about the absence of the loved one makes itself known through a certain behavior. Activities associated with the deceased person – that they used to visit, to bring sweets – are being missed now. To keep the familiar patterns intact, it is possible for someone else to take over these actions.

People with profound ID depend most of all on feelings of security and confidence. These feelings may be affected by someone dying. Daily life, with its familiar patterns such as fixed mealtimes and moments of special care, gives the person something to go by and should therefore be continued as much as possible. Counselors can help these people by offering them closeness and keeping an eye on the mood in the home. Posture, facial expression, intonation, making use of one's favorite senses, and respectful touches are important resources (Mevissen, 1999). One way of making the loss understandable through concrete experience is to create an atmosphere of remembrance. This can be done with familiar scents (of candles, for example), recognizable music or photographs, or other stimuli. One way of documenting the experience is to set up, perhaps close to his or her favorite place, a corner of remembrance containing the deceased person's photographs and characteristic belongings.

Spoken language does not aid people with profound ID toward understanding or coming to terms with their loss, but it may have a supportive function. It may help to address restless people in a low and caring voice, intonation being most important here. The shock of losing a loved one can be supported in both physical and emotional respects if counseling corresponds with people's needs in a way which facilitates the transition to the changed situation (Table 2).

TABLE 2
Experience and counseling in cases of death and grief related to profound intellectual disability

Profound intellectual disability
IQ: Up to 20/25 Intellectual age: 0 to ±2 years

Experience
- No realization of death
- Understanding is based on sensual (body-centered) impressions and experiences
- Communication is limited and nonverbal
- Development of bonding and basic security
- Reactions to death of loved one visible only from an intellectual age of 6 months
- Loss threatens build-up of fundamental confidence
- Loss mainly causes a breach of fixed patterns
- Reactions of mourning visible in behavior only after some time has elapsed

Counseling
- Offer closeness: physical contact
- Daily life with fixed patterns should be maintained as consistently as possible
- Allow people to concretely experience change
- Make people feel and see what death means
- Offer people a warm and secure atmosphere
- Important resources: posture, facial expression, intonation of voice, making use of one's favorite senses, respectful touching
- Offer concrete experiences to help cope with loss
- Let others take over behavior patterns belonging to deceased person

Severe Intellectual Disability (Intellectual Age ±2 to 4/5 Years)

Experience People with severe ID see the world around them from their own perspective. They are capable of distinguishing between their own personality and those of others, considering themselves the center of the universe. Absorbed in their own self-development, they cannot put themselves in somebody else's position (egocentric thinking). With these people, consciousness is in its formative stages, as are certain norms and values (Došen, 2005b; Mönks & Knoers, 1983; Timmers-Huigens, 1998).

At first, their reaction to death appears to be one of soberness. Asking about death, they often refer to what, how, and why (Fiddelaers-Jaspers & Fiddelaers, 1998; Stichting in de wolken, 1998). How did it happen and why now? They start to form connections between successive events (Timmers-Huigens, 1998), making the association between illness and death. They know what it means to be sick and are able to evoke specific images based on their own experience. In this phase of development, establishing connections and asking questions are stages in a growth process more characteristic of a development level of 4–5 years than of a level of 2 years.

Questions about dying are followed by those about everyday life: What's for dinner? Are we going to town tomorrow? For one thing, this shows that things that are of immediate relevance to them take up their attention. However, they may also be craving the security of daily routine. People with severe ID are intellectually incapable of grasping what dying means, although they respond emotionally. They tend to keep asking questions about death: where does the dead person go, does he go to heaven in a box, can't he fall out? Quite often, they link the concept of death to concrete experience ("that's when you're under the ground").

They consider death as something temporary, a departure such as we take when we go on holiday (Van Keersop & Van de Kerkhof, 1994). They have frequently seen a plant dying and blossoming again. Hence, it is conceivable for person with severe

ID to stand by the coffin saying, "There, that's enough now, you can get up again" or to ask, while granny's ashes are being buried, "Will there be lots of new grannies growing from those ashes now?"

Because the social environment of people with severe ID is largely made up of primary impressions, they tend to link death and grief because they see others grieving. When somebody dies, they show a reaction as soon as they become aware of the changes in others' frame of mind. Immediately after the death of a person they had known, they may show feelings of grief and start to cry. However, this reaction is more often caused by the grief observed in others than a purely individual expression. It is only at some later stage that the feelings of loss and personal grief, sometimes coupled with rage, emerge. At this level of development, too, one may observe behavior characterized by mourning, with persons withdrawing from social life or refusing to have dinner.

In a socio-emotional respect, the people described by this category strongly depend on significant others in their environment. Difficult moments may renew an intense need for closeness. For people with severe ID, imagination and reality tend to be mixed up. This is the phase of magical thinking, involving the creation of imaginary pictures to help them come to terms with death. Experiences find expression in these people's behavior, which is characterized by imagination and imitation of what others say and do. The experiences remain uncontrolled by logical thought (Fowler, 1981). The power of their imagination and their lack of realism may lead to them developing extreme fears about death and everything to do with it. Fears can become so strong as to prevent someone from admitting to himself or to others that he is suffering pain, and make him carry on his normal life when in fact there is a reality to the pain (e.g., when their hip is broken).

As far as their communication is concerned, people with severe ID do not have a vocabulary sufficient to express their grief. They cannot turn their grief into a subject of conversation. When words are spoken, they often take them literally and therefore misinterpret them. The real expression of grief is frequently managed nonverbally and through behavior. They might, for example, behave in a particularly restless manner. This stage of faith provides them with first a realization of death and, at the same time, of the taboo with which their environment turns death into something special (Fowler, 1981). Examples set by others through moods, actions, and language have a strong and lasting influence. It is therefore important how model figures deal with death and loss.

Counseling When a loved one dies, a consciousness of someone who will never return will gradually take shape in the mind of people with ID. Depending on their level of development (at the level of 2 years or of 4–5 years), people with ID may, after someone has died, become aware of the different atmosphere or different structure of daily events. They might start to ask lots of questions (the so-called "who, what and where" questions). This requires an individual approach in counseling. Apart from a thorough knowledge of mourning processes, the counselor will need to be able to offer closeness and to correctly read the signals in these people's behavior.

People going through this phase of development tend to fall back on patterns they have used in difficult situations. After the death of a loved one, someone may revert to an earlier period of his life that used to offer him security, displaying the corresponding kind of behavior. In this case, he may need stronger support when performing certain tasks, or wish to establish a closer physical contact. People with severe ID need security. They can be offered this by keeping their daily routines clear, easy to grasp, and recognizable.

To help them understand events relating to death, it is essential to make them appear as concrete as possible. Only a concrete experience is likely to create clarity and prevent people with severe ID from developing their own fantasies about what has happened. It is advisable to give them a chance to say goodbye to the deceased person, or to let them be present at the funeral. The use of visualization (by means of photographs, etc.) may also be helpful in making the moments of farewell clear, while in later stages it may help to overcome grief.

One needs to answer all their questions as exhaustively as possible, encouraging them to express what is on their mind. This last task can, to a certain extent, be carried out by means of language. If people have questions about death, the counselor should do his or her best to explain things in simple terms. People with severe ID are looking for specific explanations that they will be able to grasp ("heaven is high up above us"). As pointed out earlier, words may be taken literally and therefore misinterpreted. This is likely to lead to feelings of fear, for example, when someone says that the deceased person is sleeping (the person might refuse to go to bed for fear of not waking anymore). Fear can also be evoked by a cremation (the idea that someone is burning can cause painful associations).

Questions vary in character, from those that are easy to answer to others (the "why-questions") that will leave the counselor at a loss. In this latter case, the message that some questions just cannot be answered will suffice (Broesterhuizen, Lap, & Poppe, n.d.). Quite often, people functioning at this level have difficulties in finding the words to match their emotions. This is why concrete symbols (such as a photograph of the deceased person or a characteristic object) and farewell rituals (funeral service) are important elements in the process of coming to terms with death. In a stronger sense than words could ever do, symbols and rituals[4] make clear what has happened and give people something to hold on to during their mourning process (Van Keersop & Van de Kerkhof, 1994). The funeral, or funeral service, is a good example of this fact. The most important thing for people with ID is not a perfect understanding of what is being said in the course of the funeral service, but most of all the atmosphere, the closeness to fellow humans, and the feeling of belonging with them. This involvement may be rendered even more valuable if

[4]The concepts of "symbol" and "ritual" are explained in Figure 1.

TABLE 3
Experience and counseling in cases of death and grief related to severe intellectual disability

Severe intellectual disability
IQ: 20/25 to 35/40 Intellectual age: ±2 to 4/5 years

Experience
- Limited realization of death
- Egocentric way of thinking
- Imagination and reality tend to merge
- Beginning of linking up events such as sickness and death
- Possibility of sober primary reaction to death
- Understanding of death linked to concrete experiences
- Beginning of questioning about how and what in relation to death
- Death is seen as something temporary
- Realization of death is definite and starts to grow as deceased person is increasingly missed
- Magical thinking may evoke images of fear accompanying experience of someone's death
- Limited development of language; people cannot put emotions into words, take things literally
- Model behavior of others has strong influence on experience of death

Counseling
- Offer closeness: just be there for the other person
- Keep daily life both well organized and recognizable, with fixed patterns
- Make concept of "death" clear by concretization and visualization
- Adjust imaginary pictures of death to prevent fear
- Use specific (goodbye) rituals and symbols for grief management
- Answer questions on concrete, literal level
- Offer to play and sketch as resources for expressing emotion
- Watch own (model) behavior, make own emotions known, watch own language
- Let others take over most important patterns belonging to deceased person

there is an opportunity for the person to contribute actively to the farewell ritual in however simple a form. He may choose to light a candle, to put a flower or sketch on the coffin, or to contribute a few words or a song of his own. In coping with grief, means such as plays, stories, or sketches fulfill their role more effectively than just talking about feelings of grief. Fairy stories or anecdotes can also help to sort out emotions (Table 3).

Moderate Intellectual Disability (Intellectual Age 4/5 to 7/8 Years)

Experience To a great extent, our remarks about people with severe ID may also apply to those with moderate ID. While egocentric thought is still present, the capacity to empathize with others has increased (Došen, 2005b; Mönks & Knoers, 1983; Van Keersop & Van de Kerkhof, 1994). This phase witnesses a growing understanding of certain structures, like being able to grasp the concept of time and knowing what to make of structures relating to the family or other social features (Timmers-Huigens, 1998).

The faculty of comprehension is stronger, and so is the possibility of expressing oneself by means of language. The way in which people with moderate ID ask a question tells us that they are looking for logical explanations of what has happened (Van Keersop & Van de Kerkhof, 1994). They might reason as follows: "He was sick, that's why he's dead now. I am not sick, that's why I'm not going to die yet." In their belief that life and death take turns, their primary interest goes out to the physical, external characteristics of death. They start realizing that death is something irreversible, but it is still difficult and very confusing for them to understand what dying really means. At the same time, they begin to realize that everybody may die, and thus become subject to feelings of fear (Stichting in de wolken, 1998). Another difference in people with moderate ID is that they react to bereavement in a more dependent fashion. They feel particularly vulnerable because they have a greater power of reason, but at the same time they remain incapable of adequately dealing with the information (Stichting in de wolken, 1998).

They realize more clearly that other people react to someone's death by showing certain emotions, but more often than not they lend their own coloring to these emotions. After a loved one has died, for example, they may overhear a comment that this is too sad because now the deceased person cannot come along on holiday. This as a rule makes them grieve because they can see the sadness of the situation (Stichting in de wolken, 1998; Van Keersop & Van de Kerkhof, 1994). Imagination and reality still tend to be mixed up, while the awareness of reality is growing steadily. Magical thinking still has a strong effect on certain ideas and feelings. This may cause feelings of guilt for imagined causality between the death and recent disagreements or harsh words with the deceased. They may believe they can ward off certain problems, such as sickness and death, simply by making the sign of the cross every morning (Broesterhuizen et al., n.d.; Fowler, 1981).

Even people at this level of development may first of all react with soberness to the announcement of somebody's death. Thus, a person might point out the corresponding newspaper announcement and explain that he is looking forward to the funeral service. This just proves that they relate a lot of what is going on to themselves only. Crying must be considered primarily as a reaction to the grief of those around them. These people often allow themselves to be governed by spontaneous impulses. Mourning behavior will emerge at a later point in time. Thus, reactions of grief tend to occur at the moment the loss is being experienced, or when the realization of irreversibility starts to sink in. To a certain extent, people with moderate ID are capable of putting their emotions into words. There is more verbal communication with regard to the concept of death, and to what

happens when somebody dies and how things are believed to go on. At this stage of faith, the experience of magical thinking will, up to the age of 6 years, occupy the foreground. Objects that may be associated with death or with the deceased person are experienced as death itself or as the person that has died (Fowler, 1981).

Counseling People in this phase of development are likely to undergo a lot of grief as the moment of saying goodbye to a dying person draws near. In the long term, a deceased person will be missed in every possible respect. For an extended period, there will be questions regarding the why and the how because the power of comprehension is stronger. These people are searching for logical explanations. It is important, then, to have ready clear answers to their questions. Only with the help of such answers is it possible to create both a consciousness of the irreversible nature of death and an adequate management of grief. People with moderate ID may be hesitant in accepting an explanation of why the familiar person has died because the characteristics of death are rarely encountered in daily life. Death is not something one can concretely show to another person, and thus it is rather difficult to understand.

Counseling should orient itself toward making clear what death means and toward grief management. To support comprehension, counselors may use stories about life and death, photographs, and farewell rituals. But as with all people, counseling starts at the very point where the person with ID is actively involved in the process of someone else's dying and where he or she is given the opportunity to say goodbye in the way he or she wishes to do so. Another point is when all mourners are rallied together to talk, to look at photographs, and to visit the churchyard. Repetition of death-related rituals is a means of learning something and is essential in helping understand death and bereavement.

Offering the bereaved person a feeling of closeness by just being there when things get tough best starts grief management. Talking about the events and the emotions they have raised may provide additional support. The use of rituals and symbols can help to put grief in its proper place. To help do so, a book of memories or lighting a candle for the dead person may be used (Van de Wouw, 1988). The symbols and rituals may have a somewhat less concrete character than those employed to aid people with severe ID. A reference symbol such as a cross can refer to death and will be met with understanding.

Persons functioning at the level described in this section are more likely to express their emotions verbally, or indirectly by means of behavior and play. It is essential that they be able to express themselves freely and with confidence. It is the counselors' prime task to correctly interpret certain utterances as signals of grief. The bereaved may be given support by other loved ones, for example, through reminiscences about the deceased. The bereaved, however, do not only ask for support in their own grief, but frequently offer help to their counselors. If the counselors show themselves receptive to such moves by demonstrating their appreciation, the influence on the person with moderate ID will be a positive one (Van de Wouw, 2000). As experience has taught us, people with moderate ID will themselves indicate the limits of what they want to do or what they feel capable of doing with regard to the death of a loved one. They deserve our respect for making this choice themselves (Van de Wouw, 2000).

In summary, it is essential to underline that normal daily life in all its familiar aspects should continue for people with moderate ID. Deriving positive experiences from new situations, they can start to build up fresh confidence (Table 4).

TABLE 4
Experience and counseling in cases of death and grief related to moderate intellectual disability

Moderate intellectual disability	
IQ: 35/40 to 50/55	Intellectual age: 4/5 to 7/8 years
Experience	
Limited realization of death	
Basic capability of putting oneself in another person's place	
Projection of own feelings onto other person	
Development of insight into specific structures, such as time and family	
Stronger comprehension and more pronounced means of expressing emotions in language	
Growing sense of reality	
Searching for logical explanations of death	
Comprehension of death grows, but people are still unable to put everything in its proper place and become confused; they need specific explanations which are not (always) ready at hand	
Growing comprehension of the irreversibility of death	
Sober primary reaction to death	
Feelings of guilt and fear as reactions to other people's grief	
Reactions of mourning emerge at a later point in time	
Counseling	
Offer closeness: just be there for the other person	
Make being dead a concrete concept	
Resources: visualization, concretization	
Help to cope with grief	
Make use of rituals and symbols	
Offer the opportunity to express grief	
Make use of stories, plays, sketches, life stories and photographs	
Give logical explanations to questions, make connections visible	
Call deceased person to mind, talk about him	

Mild Intellectual Disability (Intellectual Age 7/8 to ±12 Years)

Experience People with mild ID are capable of defining themselves and their environment. They can experience and sort out events, and they proceed from the social rules and norms they

have already made their own. There is a growing insight into the concept of time and other structures (e.g., worldview, social relationships) (Timmers-Huigens, 1998). The people described in this section are capable of logical thought coupled with specific concepts (Došen, 2005b; Mönks & Knoers, 1983; Van Keersop & Van de Kerkhof, 1994), such as cause–effect relations. This includes, for example, their ability to realize that a person who is incurably ill will eventually die. It shows a conscious realization of death. People functioning at this level of development can form a realistic image of what it means to be sick and to be dying. They are aware of death's irreversibility (Kester, n.d.; Stichting in de wolken, 1998; Ter Haar & Joseph, 1989; Van Keersop & Van de Kerkhof, 1994). Emotions that characterize the moment of saying goodbye make themselves felt as soon as the serious illness of the person in question becomes apparent.

As a rule, we would posit that the people described here go through processes of bereavement comparable to those of other people. It should be mentioned, however, that people with mild ID tend to be more impulsive in their reactions than others. When they are grieving, they will let their environment know. They do not hide their feelings only because these would be inappropriate to the situation (Broesterhuizen et al., n.d.; Van Keersop & Van de Kerkhof, 1994).

After the death of a loved one, people with mild ID may display emotions comparable to others, such as denial, a feeling of desperation, and strong emotional outbursts, such as crying or anger (Kübler-Ross, 1984). Apart from an interest in all external things relating to a death, they are eager to know about what happens afterwards. They start thinking about the mystery of life and death, looking for explanations. Death evokes fear because not everything pertaining to it can be explained and understood. In this phase, death is not yet seen as inevitable or as something affecting everyone. (Ter Haar & Joseph, 1989). People with mild ID are moderately capable of putting themselves into someone else's position and expressing their sympathy. As far as their feelings are concerned, however, they consider the reactions of others in the light of their own experience. If, for example, someone asks them how they feel after a companion's death, they will react by saying that the person asking is probably very upset himself or he would not be talking about this. It is only when they reach the intellectual age of 11–12 years that a capacity for sympathy for the grief of fellow human beings develops. They usually realize that there is a future and a past. They realize as well that a loss is something permanent. It has often been noted that during the process of bereavement, some may suddenly start to perform worse than before or show signs of physical (psychosomatic) disorder.

As far as their powers of communication are concerned, they make a more extensive use of language than people with moderate ID. Endowed with a more pronounced faculty for reasoning, they can have talks about death. Death and its related processes, such as mourning, can be discussed and explained. There is a strong need in these people to be able to talk things over with someone (Van der Stap & Torenbeek, 1995). In the experience of those with mild ID, the deceased person continues to occupy a specific place. This place, usually resembling a familiar environment, can be described down to the last detail. The person believes it possible to establish a mutual contact with the deceased person and that the deceased are capable of influencing life and the living. "Death" is something or somebody. Objects that remind them of death tend to inspire the people not only with strong emotion, but also with fear. There is a conviction that dying has something to do with justice and sincerity (Fowler, 1981).

Counseling Like all others with ID, those adults we have been discussing in the present section need closeness as much as they need to be able to share their grief throughout the sickness and death of a loved one. For them, rituals and symbols may be used to good effect in coping with bereavement. It should be added, though, that people with mild ID may ask questions to which there is no satisfactory answer. Euthanasia and life after death are cases in point. In situations such as these, it is important to take the person seriously and to answer with sincerity. People with mild ID are more likely to put questions to seriously ill persons that others would not dare to ask. They are real questions expressing real feelings. It is essential that these feelings and questions be taken seriously, even if the questions are difficult or, ultimately, unanswerable. A counselor should try to find out just what prompts such a question. Is the person sitting in front of him scared; is he scared of the unknown or perhaps of being the sole survivor in the family? Does concern or grief play a part? Such issues should be considered before answering the question (Van Keersop & Van de Kerkhof, 1994).

People with mild ID need appreciation for the way they give sympathy and care to others. If a responsibility is assigned to them while the loved one is dying or when the moment of saying goodbye has come, they feel appreciated. They can be involved in the funeral arrangements or in the execution of the memorial service or funeral. They can help simply by lighting a candle, by saying a few words about the deceased person, or by putting a letter or sketch on the coffin. They are capable of letting their counselors know what exactly they want and feel able to do. Stories (e.g., others' biographies or those found in religious texts) may help to put the sad event and the grief into their proper place. Although such stories are likely to evoke strong emotions, they can also help put the things being experienced into context and thus render them understandable (Table 5).

DISCUSSION

Our intent in framing this article was to explore and describe the way in which people at different levels of ID may handle death and mourning. Consideration of each level yielded specific forms of behavior to match these events. We have conceptualized what we believe to be a useful guide for structuring the work of aiding grief and bereavement among persons who may have difficulties

TABLE 5
Experience and counseling in cases of death and grief related to mild intellectual disability

Mild intellectual disability
IQ: 50/55 to 70 Intellectual age: 7/8 to ±12 years

Experience
- Clear realization of death
- Persons know how to define themselves by comparison with others
- Growing insight into specific structures (worldview)
- Logical thought coupled to specific events
- Empathy present, but experienced from own perspective
- Realistic image of meaning of death
- Realization of irreversibility of death
- Mourning processes comparable to those of nonhandicapped people
- Think and talk about mystery of life and death
- First questions about "why and what for"

Counseling
- Offer closeness: share bereavement experience
- Talk about what has happened; call memories to mind
- Make use of rituals and symbols to cope with grief
- Take questions seriously; try to find out which feelings lie behind reactions
- Allow participation in farewell ritual
- Allow task and responsibility in farewell ceremony

forming appropriate reactions to personal change and loss. We see this as helping bridge practice and understanding of people with ID and their abilities to address this heretofore relatively unexplored area. We also see our framework as serving as stimulus for further research and discourse of clinical practice.

However, we also wish to raise some caveats. The stages of development and forms of behavior that we have discussed should not be considered as static facts. Far from being absolute entities, the stages merge into each other. Each individual goes through his or her very own development that is shaped by the experiences he or she has undergone in life. Thus, progressions from one stage of development will blend with another, and it is essential to successfully complete one phase before one can continue growing in the next. In counseling, a great many aspects that are important for everyone concerned may appear again and again. One of these aspects is the fact that a person needs to be able to let go and say goodbye while being able to rely on the closeness of others.

Apart from knowledge of how to deal with death and bereavement in a context of development stages, there are other important issues, such as concretization and visualization, which we have not explored in depth. The following subjects, among others, should not be neglected: how to cope with one's own sickness and death (terminal care), important decisions concerning the end of life, the question of how far medical measures may go, and the taking of steps to prolong life. It is not always easy for a person to handle such questions adequately while also trying to come to terms with his or her own feelings of grief.

The subjects of death and of grief management are central, and we would like to stress that apart from death, there are other instances of having to "say goodbye." At some point in their lives, people with ID, like anyone else, may have to say goodbye to friends or relatives for other reasons than those focused on here. This happens, for example, when a companion moves or leaves because he or she has taken on a different job. Even such a parting, while less dramatic, may be coupled with separation grief, so that those involved will need to be supported (Blackman, 2003; Kauffman, 1994).

In closing, we wish to state that grief is a part of bereavement. It is a normal process that needs support, but whose problematic aspects need not be solved all at once. If someone needs to share his story or emotions, he should be able to do so. He should be able to find a person willing to listen. It is important for people to be there for each other. The experience of others being close and the renewed experience of something positive will help create a new perspective for the future.

ACKNOWLEDGMENTS

This project was initiated and financed by the National Information Network for the Care of the Handicapped in the Netherlands. The European Network on Intellectual Disability and Aging (ENIDA) provided funding for the translation into English by C. Roes. We acknowledge Dr. D. Henning for her helpful comments in the formulation of the text.

REFERENCES

American Psychiatric Association. (2000). *DSM-IV-TR diagnostic and statistical manual of mental disorders.* Washington, DC: APA.

Blackman, N. (2003). *Loss and learning disability*. London: Worth Publishing.

Bornell-Pascual, E., Huline-Dickens, S., Hollins, S., Esterhuyzen, A., Sedgwick, P., Abdelnoor, A., & Hubert, J. (1999). Bereavement and grief in adults with learning disabilities: A follow-up study. *British Journal of Psychiatry*, *175*, 348–350.

Broesterhuizen, J., Lap, S., & Poppe, S. (n.d.). *Rouwverwerking bij mensen met een verstandelijke handicap*. Zoeterwoude, the Netherlands: Swetterhage. (2005).

Child Development Institute. (2005). *Stages of intellectual development in children and teenagers.* Retrieved on October 10, 2005 from http://www.childdevelopmentinfo.com/development/piaget.shtml

Dodd, P., Dowling, S., & Hollins, S. (2005). A review of the emotional, psychiatric and behavioural responses to bereavement in

people with intellectual disabilities. *Journal of Intellectual Disabilities Research*, *49(Pt 7)*, 537–543.

Došen, A. (2005a). Applying the developmental perspective in the psychiatric assessment and diagnosis of persons with intellectual disability: Part 1 – Assessment. *Journal of Intellectual Disability Research*, *49*, 1–8.

Došen, A. (2005b). *Psychische stoornissen, gedragsproblemen en verstandelijke handicap. Een Integratieve Benadering Bij Kinderen En Volwassenen.* Assen, the Netherlands: Koninklijke Van Gorcum b.v.

Fiddelaers-Jaspers, R., & Fiddelaers, J. (1998). *Kinderen en de dood.* Heeze, the Netherlands: Stichting In de wolken.

Fowler, J. W. (1981). *Stages of faith: The psychology of human development and the quest for meaning*. San Francisco, CA: Harper.

Harper, D. C., & Wadsworth, J. S. (1993). Grief in adults with mental retardation: preliminary findings. *Research in Developmental Disabilities*, *14(4)*, 313–330.

Hollins, S., & Esterhuyzen, A. (1997). Bereavement and grief in adults with learning disabilities. *British Journal of Psychiatry*, *170*, 497–501.

Kauffman, J. (1994). Mourning and mental retardation. *Death Studies*, *18*, 257–271.

Kester, G. (n.d.). *Help kinderen de dood te begrijpen*. Enschede, the Netherlands: Ardanta B.V. Uitvaartverzorging.

Klass, D., Silverman, P. R., & Nickman, S. L. (1996). *Continuing Bonds: New Understandings of Grief*. Washington, DC: Taylor and Francis.

Kübler-Ross, E. (1984). *Kinderen en de dood*. Baarn, the Netherlands: Ambo.

Mevissen, L. (1999). *Interactie begeleider – Cliënt in relatie tot het sociaal emotionele ontwikkelingsniveau*. Veldhoven, the Netherlands: Severinus.

Mönks, F. J., & Knoers, A. M. P. (1983). *Ontwikkelingspsychologie: inleiding tot verschillende deelgebieden*. Nijmegen, the Netherlands: Dekker & Van de Vegt.

Piaget, J. (1954). *The construction of reality in the child* (M. Cook, trans). New York: Basic Books.

Stichting In de wolken. (1998). *De meest gestelde vragen over kinderen en de dood*. Heeze, the Netherlands: LPU, in cooperation with NUVU.

Ter Haar, A., & Joseph, K. (1989). Boeken tegen verdriet. *Leesgoed*, *2*, 8–11.

Timmers-Huigens, D. (1998). *Mogelijkheden voor verstandelijk gehandicapten*. Maarssen, the Netherlands: Elzevier/De Tijdstroom.

Van de Wouw, W. (1988). Afscheid nemen. *Voorzet*, *1*, 9–12.

Van de Wouw, W. (2000, September). *Omgaan met verliessituaties bij mensen met een verstandelijke handicap.* Paper Presented at the 2000 Annual Meeting of ENIDA, Maastricht, the Netherlands.

Van der Stap, J., & Torenbeek, K. (1995). *Gedrag en ontwikkeling vanuit Z-verpleegkundig perspectief*. Leiden, the Netherlands: Spruyt, Van Mentgem, & De Does.

Van Keersop, G., & Van de Kerkhof, R. (1994). Hoe verstandelijk gehandicapten omgaan met ziekte, dood en rouw. *Voorzet*, *7*, 9–14.