Advance in Psichology and Education

Mourning and disability

Beatriz Garvía Peñuelas
Psicóloga especialista en psicología clínica. Coordinadora del Servicio
de Atención Terapéutica y Psicóloga del Centro Médico Down.
Barcelona. Spain

Correspondence: beatriz@fcsd.org

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Abstract

People with intellectual disabilities undergo mourning over all kinds of bereavement. The worst and most painful is the loss of a loved one. The general stance for a long time was to keep them away from the reality of bereavement in an overly protective manner, to prevent suffering. However, with the necessary support, people with intellectual disabilities are able to handle and process painful experiences and emerge all the stronger, like the rest of the population.

The present article defines mourning and its processes, considers how death is represented in the mind of a person with intellectual disabilities, and defines normal versus pathological mourning.

Finally, some considerations are offered on appropriate attitudes for family members or caregivers in the face of imminent or recent bereavement, in order to help the person with a disability through the mourning process and provide the requisite support.

Keywords. Mourning. Disability. Dysfunctional grief.

Mourning can be understood as the way we react to a loss. We all go through times of mourning that affect our thoughts, our feelings and, meanwhile, our activities. We mourn the death of a loved one, but mourning can also stem from other types of loss - a job, a friend, a personal belonging with sentimental value, our health, a stable situation or a partner following separation.

Mourning is rarely broached when dealing with people with intellectual disabilities due to myriad fears and prejudices regarding their assumed inability to mourn, all of which thwart contact, communication and understanding of their emotions and feelings. Whilst a person with a disability may conceive of death differently because they have greater difficulties and are less informed, the pain of loss is the same. One particularly rife prejudice is that they will not be able to cope with the grief, that the mourning process will not develop well or that serious depression will ensue, which is also why 'preventive' medication is often prescribed, before even assessing whether it is necessary.

People with an intellectual disability are given few opportunities to talk through their bereavement because their suffering is not tolerated: perceived and treated overprotectively, they are confined to an inexistent, spurious world where nothing is wrong, which may cushion the surroundings but also cuts them off. The news is hidden from them and an air of optimism is kept up for their benefit. This type of behaviour prompts them to clam up and not ask questions, in order to protect themselves and the adults around them. «Sometimes I cry about my dead grandparents,» said one 20-year-old man with Down syndrome, «but I can't tell my mother because it makes her sad».

Another young man, aged 27 and also with Down syndrome, whose father is seriously ill said, «I don't ask how he's doing because my mother gets upset and nervous. He must be in a bad way».

«My grandmother has died,» reported a 25-year-old young woman with the same disability. «I took four days off work to think about it but I don't know where she's gone. How can she have gone to heaven? I saw her dead and I wanted to jump into a void. At night I can see her face and I can't sleep. I can't tell my mother - she won't listen to me».

Other remarks from young adults between the ages of 20 and 30 with Down syndrome reveal their concerns about death:

– «I'm scared stiff of death. One day my mother said we were going to the cemetery and even though I don't understand this big mystery I'm afraid of it».

– «I don't know what's happening inside me - could it be my dead family? I feel pain inside, and fear of death»…

Grief and suffering are inevitable but they do help us to grow. For suffering to be useful rather than destructive we must learn how to handle it. And the same goes for people with a disability, who also feel sadness, anger, anxiety and the whole spectrum of feelings involved in mourning, with the only difference that they need more support to get through it.

The mourning process

Laplanche and Pontalis define mourning as the «intrapsychic process, occurring after the loss of a loved object, whereby the subject gradually manages to detach himself from this object».

The mourning process is essential to avoid depression and other psychopathological conditions because whenever there is bereavement there is always mourning. People with intellectual disabilities need more support throughout this process because when they come face to face with serious illness or death they either relocate it in the adult world or isolate it and take a childish stance to it, according to how they process the situation and the help they receive.

Representing death

In some aspects people with Down syndrome may never proceed beyond a particular stage of psycho-emotional development in their growth. When this occurs the subject's behaviour is only partially in fitting with their current stage. Death, which is an abstract concept and requires symbolic intelligence in order to be understood, is variously represented according to chronological age.

In early childhood the child associates death with the idea of absence. Life means presence and death equals absence. Many people of all ages with a disability never get beyond this phase («s/he's gone to heaven»). This concept is upsetting because its undercurrents are feelings of abandonment and guilt («I was bad so I've been abandoned»), although there is always the hope of a return and the search for the lost person.

«I can't sleep at night thinking about death; the news said that we will be reincarnated. It's better to die in the early hours of the morning; that way you're born again» (spoken by a 22-year-old with Down syndrome).

Other examples from young people with Down syndrome:

… «My grandmother went when she was 75. When she comes back I'll see her».

«My grandmother died. She was 92 and I don't see her anymore because she's gone to find a new life. Did she disappear? I don't know. I get depressed and anxious talking about this. It upsets me. I think of my parents, they're old, I'm sure she'll come back».

Later, the concept of death as synonymous with stillness emerges: whatever moves and carries out certain functions, such as eating, is alive, and what is still is dead. At this age there are feelings of guilt and it is hard to accept change and cope with feelings such as nostalgia, anger or grief. Some people with a disability also get stuck at this developmental phase, even when they become teenagers and adults.

One 24-year-old male with Down syndrome who had been to Accident and Emergency three times for anxiety attacks since the death of a relative told me, «I do a lot of activities because it gets me moving a lot. If I'm not on the move I get bored and it frightens me. Dying is painful and it scares me. When you're dead you can't move or go anywhere».

The irreversible nature of death is perceived around the age of 9 or 10. The child begins to acquire an adult understanding of death, and this is when the specific fear of the death of one's parents develops. Many adults with a disability can also be found at this stage:

«I'm worried about my parents, about them going. I'm really scared of death. What does it mean to die? I'm writing things on my computer about life and death, accidents and stuff. The verb to die is morbid, it's forever. My dream is to live,» said one 26-year-old woman with Down syndrome.

It is in adolescence that death takes on its abstract nature. Teenagers have the same understanding of death as adults, but their changing nature results in them lurching between acceptance and denial, between feeling immortal and wanting to die. The universal nature of death - the fact that not only the elderly die - is the hardest pill for people with a disability to swallow. The attitudes and defence mechanisms they may employ when faced with the notion of death are contingent upon a range of factors and can manifest themselves as a lack of interest (not wanting to know) or as excitability, instability, anxiety and aggressiveness. A regressive stance may also be adopted.

«I can't talk about my brother's death; he was knocked over by a car and he was young. Until then I thought only old people like my grandfather died,» reported a 19-year-old woman with DS.

The notion of a necessary death is dependent upon full understanding of sexuality and the concept of reproduction (consider the mistaken beliefs that many people with a disability have of these topics). Being able to accept one's origins corresponds to being able to accept one's end. Death is seen as a biological process associated to old age:

«I heard my mother saying to a doctor that when I was born she wanted me to die, because of the syndrome, but that now she really loves me. Can babies die? Why are we born with the syndrome? Do you die when you're old or can it be when you're young as well?»

«They abandoned me, they left me on my own in an incubator. Before her bones started to hurt my mother was young and she was really good-natured. Then she got old and her bones hurt and now she's tired of working.» «She'll die soon, her time is up.» Remarks made by a 31-year-old woman with Down syndrome.

Taking mourning as a paradigm, another type of mourning that people with a disability go through has to do with accepting their disability or the 'loss of normality'. Labels such as disabled, deficient, subnormal and handicapped pigeonhole a person in such a way as to exclude them from normality, causing anxiety and confusion.

«Am I retarded? Am I mad? Do you know what mad people do? They get down on their knees and rock backwards and forwards. I'm scared of being mad, because of the syndrome… Am I mad? Am I normal?» (The thoughts of an adult with Down syndrome.)

Clearly, people with intellectual disabilities are perfectly capable of expressing their fears about death, even when their psycho-emotional stage is lower than that of their age group. This does not mean they should be treated like children or overprotected or that the truth be hidden from them. On the contrary, we should be guided by their chronological age and personal maturity, giving clear messages and making ourselves understood.

Symptoms of mourning

Over the various stages of the mourning process there are several possible general symptoms that may appear in isolation or together, such as: an overall slowdown; loss of motivation; guilt; loss of appetite; sleeplessness; depression; isolation; apathy or hyperactivity; negative thoughts; ideas of death; altered behaviour, and somatisation.

People with a disability sometimes appear to be indifferent to bereavement, giving the impression they are not grieving. This is not because they feel no pain but because they are struggling to express it. Instead, they resort to various types of behaviour: manifest sadness, regression, loss of abilities, loss of appetite, somatic disorders, sleeping disorders, eating disorders, anxiety, behavioural changes, and isolation. All of these behaviours point to profound inner turmoil.

Normal mourning

Mourning is a normal, natural response to a loss. Although each individual tackles it in their own way, there are some common reactions. It is a process of adaptation that serves to restore the balance and enable maturity, acceptance and adjustment to the loss, as well as a healthy return to life in a world where a loved one is no longer present.

People with intellectual disabilities also go through a process of mourning, and it is down to us to recognise its symptoms (grief, rage, behavioural disorders). Their mourning can evolve appropriately provided that the wool is not pulled over their eyes, the event is clearly explained to them, they are allowed to talk about the bereavement and their grief, and they are given the right support.

The mourning process ends when a person can talk about the deceased loved one with signs that they have accepted the loss.

Dysfunctional or pathological mourning

Pathological mourning occurs when a person has not reached or finalised the various stages in the process and feels guilty for the loss and threatened. The individual may react as if they are not grieving or manifest unusual physical symptoms or repeated bouts of depression.

People with a disability can also suffer pathological mourning, causing pathological responses that jeopardise their health. They may also undergo severe depression and even disorders of a psychotic nature. Pathological mourning can take hold over a person and drag on, giving rise to symptoms such as anxiety, sadness and/or behavioural disorders, irritability and so forth.

According to Kerim Munir, a psychiatrist at Harvard Medical School, mourning results in a lasting disorder in one out of five people with intellectual disabilities. Special care must therefore be taken and they must be given regular counselling and support. People who go through an extended period of mourning may benefit from the right type of therapy to help them get over it.

Bereavement often entails a dramatic life change for people with a disability. The death of one's parents, specifically, not only means losing loved ones but leaving behind a whole way of life (the home, neighbourhood and neighbours) as the individual is taken into care by other relatives or an institution. This happens without due explanation and without proper understanding, leading to intense anxiety and severe depression.

The anguish surrounding death felt by people with an intellectual disability is bound up with feelings of abandonment and loss of love. A young man with a disability of unspecified origin was well prepared for the death of his father following a protracted illness. He experienced the illness, participated, went to the mortuary, said goodbye to his father, but keeps his urn in his bedroom and talks to him. He needs this 'presence' (he cannot symbolize it) so as not to feel abandoned.

The family may react inappropriately to bereavement by becoming extremely overprotective or displaying symbiotic attitudes (the son sleeping with his mother following the father's death) which hamper the mourning process and increase the likelihood of regression and entrenchment.

The right thing for the family to do in these cases is to share the illness and even the agony with their child with a disability, despite the anxiety and possible destabilising effects. They must not be cut off from it.

How we can help

People with intellectual disabilities in mourning need support, help and understanding as they are particularly vulnerable to loss. They must be kept continually informed, without pretence, about the situation and how it is changing. The information must be given gradually in language that is clear, in a manner that is suitable to their level of cognitive development and in accordance with their tolerance, breaking it down into few concepts at any one time. Any questions must be answered directly and simply and the person must be allowed to say goodbye.

Mourning is a subject that should be dealt with at school so as to help children learn to accept suffering, illness and death, since loss is part and parcel of life. It is vital to aid understanding of it, without taboos and clichés, using examples from daily life (the death of a pet, a plant or a celebrity). We must also devote time to it and show our trust for the person with a disability to express their feelings and handle it their own way by making them part of the events related to dying, of the support of friends and loved ones in commemorating birthdays and expressing feelings on important dates as all of this contributes to the healing process.

Other ways of easing the process are keeping to normal routines as much as possible, finding new activities to do, making new relationships, doing special activities for a change from the everyday and avoiding isolation.

To conclude, people with intellectual disabilities, like the rest of the population, go through periods of mourning which must run their natural course. Mourning is a painful experience, but when handled properly painful experiences result in psychological growth and personal maturity. To this end, we must not conceal or deny loss but provide the right foundations so that people with a disability can be informed and receive the support needed in order to cope with it.

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News

11th RAMON TRIAS FARGAS AWARD FOR DOWN SYNDROME RESEARCH - 2009

All work that meets the following requisites is eligible for this award:

1. Unpublished research work carried out in Spain in the last three years. Originality and scientific interest will be valued. The topic covered must be medical and related to Down syndrome (genetic, perinatological or medical in general), excluding antenatal diagnosis.
2. The work can be presented in any of the official languages of Spain.
3. The length must be no less than 20 A4 pages in double space, and no longer than 50 pages.
4. Candidates can apply individually or as a group, with backing from scientific, academic or other institutions related to Down syndrome, both public and private.
5. In order to ensure anonymity, no data or names of places, people or institutions that could reveal the identity of the candidate/s should be contained in the reports. The work shall be identified by a pseudonym and the bibliography included in the text must be numbered.
6. Candidates must present three hard copies of the work or one hard copy and one electronic copy. The original report including all sources of identification (names of authors, bibliography) and the electronic original must also be submitted in a closed envelope bearing the pseudonym.
7. The total prize money is €6,000. The jury may award the full sum to one single piece of research or split it between a first prize and two second prizes of €1,000 each.
8. The deadline for submission is 9 October 2009.
9. If deemed appropriate, the winning report will be publishing in the Catalan Down Syndrome Foundation magazine. Notwithstanding, the authors retain the right to publish it at a later date in other medical journals.
10. The Jury shall be made up of three personalities from the field of science. Their verdict shall not be open to appeal.
11. The Jury may declare the award null and void if the work presented is not of the required standard.
12. The result will be announced in the last week of October 2009. The award will be presented at the 10th International Down Syndrome Congress which will be held on 12 and 13 November 2009.
13. Written acceptance of the competition rules signed by all of the authors must be submitted with the originals. The authors' addresses, telephone numbers and other contact details must also be included.
14. All documentation must be sent to Fundació Catalana Síndrome de Down, Comte Borrell, 201-203, 08029 Barcelona, either by registered post or a courier service. Please state on the envelope: "Premi Ramon Trias Fargas d'Investigació sobre la Síndrome de Down".
15. All work that does not receive an award shall be returned to the authors.

Xavier Pascual, the Vice President of Toshiba South Europe Information System, visits the Catalan Down Syndrome Foundation to sign the Collaboration Agreement that has been in place between Toshiba and our organisation since 2006.

This year Toshiba will be giving us 10 laptops and 3 desktop computers. Furthermore, Toshiba and the Catalan Down Syndrome Foundation will also be kicking off a research project on changes in learning amongst 3- to 5-year-olds, underpinned by use of new technologies.