

Can you fall out of heaven?



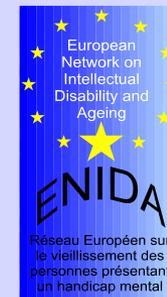
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Can you fall out of heaven?

Experience of death and management of grief in people with intellectual disability

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Content

- Death (of others) and bereavement:
 - Background information and goal of the brochure
- The experience of death related to the level of ID and socio-emotional age
- Discussion

On beforehand

- Loss is not only in death but also in:
 - Moving from home to residential care
 - Moving of co-residents
 - Change of staff
 - No own family life
 - Physical handicaps
 -

Death and bereavement

- In recent years, taboos surrounding death and bereavement have been decreasing, also for people with intellectual disability
- However, death is still sometimes completely kept from people with ID
 - ‘they wouldn't understand it anyway’
 - ‘they shouldn't be unnecessarily confronted with grief’
- Increasing attention for death, dying, palliative care in practice and research

Death and bereavement

- Involvement is important for having adequate room to bereavement and to mourn effectively
- Not being involved can cause psychological complaints such as continuous exhaustion or depression



Reactions of people with ID

- Fleeting reactions (‘no’ emotions)
- Inappropriate reactions (‘are we still going to the zoo?’)
- **Reactions depend on level of ID, socio-emotional age, stages of faith**



Differences in development

- often there are considerable differences between intellectual and socio-emotional ages (much lower)
- discrepancy between levels of development can cause psychological and behavioural problems



Goal

What:

- the goal is to make clear how people at different levels of intellectual disability **experience and handle** death and mourning
- Insight in how to **counsel** them in grief, bereavement and mourning

Why:

- Help family/counsellors to **understand the behaviour and reactions**
- Family/counsellors can **support** persons with ID
 - in their grieving/mourning/bereavement
 - who are dying

Used theories

- Piaget (cognitive development)
- Došen (socio-emotional development)
- Timmers-Huigens (strategies of ordering experience)
- Fowler (stages of faith)



Used theories

Kübler-Ross model; Stages of grief

1. Denial:

"This can't be happening"

2. Anger:

"It's so unfair"

3. Bargaining:

"I'll do anything, if I only get better"

4. Depression:

"I'm sick, nothing matters anymore"

5. Acceptance:

"I will cope with it, and enjoy all things I still have"

Developmental level

| Level of impairment | IQ | Intellectual age |
|---------------------|-----------------|----------------------|
| Profound ID | tot 20/25 | 0 tot ±2 jaar |
| Secere ID | 20-25 tot 35-40 | ±2 tot 4 à 5 jaar |
| Moderate ID | 35-40 tot 50-55 | 4 à 5 tot 7 à 8 jaar |
| Mild ID | 50-55 tot 70 | 7 à 8 tot ±12 jaar |

Profound ID, experience

IQ: up to 20/25 Intellectual age: 0 to \pm 2 years

Experience:

- No realization of death
- Communication is limited and non-verbal
- Understanding is based on sensual (body-centred) impressions and experiences
- Reactions to death of loved one visible only from a intellectual age of six months
- Loss threatens build-up of fundamental confidence
- Loss mainly causes a breach of fixed patterns
- Will not experience the stages of grief
(at least, they do not show it clearly)

Profound ID, counselling

- 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
- Important resources: posture, facial expression, intonation of voice, making use of one's favourite senses, respectful touching
- Offer concrete experiences to help cope with loss



Severe ID, experience

IQ: 20/25 to 35/40

Intellectual age: \pm 2 to 4/5 years

- Limited realization of death
- Egocentric way of thinking
- 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



Severe ID, experience

- Death is seen as something temporary
- Realization of death starts to grow as deceased person is increasingly missed
- Limited development of language; people cannot put emotions into words, take things literally
- Model behaviour of others has strong influence on experience of death
- Will not experience the stages of grief
(at least, they do not show it clearly)

Severe ID, counselling

- 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
- Let others take over most important patterns belonging to deceased person



Moderate ID, experience

IQ: 35/40 to 50/55

Intellectual age: 4/5 to 7/8 years

- 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 (time, family)
- Stronger comprehension and more pronounced means of expressing emotions in language



Moderate ID, experience

- Searching for logical explanations of death
- Still unable to put everything in its proper place and become confused
- Growing comprehension of the irreversibility of death
- Feelings of guilt and fear as reactions to other people's grief
- Reactions of mourning emerge at a later point in time
- Will experience the stages of grief

Moderate ID, counselling

- Offer closeness: just be there
- Make being dead a concrete concept
- Visualization, concretization
- 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

...hoe het oma was en leest een gedicht voor.



Jeroen legt ook bloemen op de kist van oma.

Mild ID, experience

IQ: 50/55 to 70 Intellectual age: 7/8 to \pm 12 years

- Clear realization of death
- 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, irreversibility of death
- Mourning processes comparable to those of non-handicapped people, but more impulsive
- Think and talk about mystery of life and death
- First questions about 'why and what for'
- Will experience the stages of grief

Mild ID, counselling

- 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



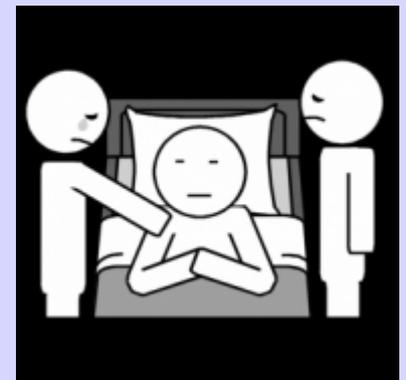
Discussion

- The stages of development and forms of behaviour are no static facts, the stages merge into each other
- Be aware of the discrepancy between the intellectual and emotional level
- Adults with ID function at a comparable level of thought as children, BUT they are different from children and should not be treated as such.



Discussion

- Apart from death, there are other instances of having to say goodbye (a companion moves or a counsellor, took on a different job). Such a parting also may be coupled with grief
- Grief is a part of bereavement. It is a normal process that needs support, but whose aspects need not be solved at once



For close others...

Emotions –because of knowledge about the disease and perspectives- are logical and natural, and thus all right

but may affect the persons with ID

Professionals:

- Focus on needed support
- Take care of balance between closeness and professional distance

Conclusions

- Grief, mourning and bereavement are normal processes that need support, also in persons with severe/profound ID
- Based on existing theories, it is possible to start revealing the topic and offering adequate counselling

Thank you!



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