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Humanitarian Aid and Civil Protection

Reactions and needs of persons with mental disabilities in emergencies and disasters

Information for caregivers

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General Information

Acute stress reactions as perceived by the experts

General/mental disabilities

- Same response and needs as individuals without impairment
- Do not forget individuality of a person´s reactions, needs and coping strategies!

Specifics for persons with mental disability

- Greater intensity of reactions and needs than in individuals without disability
- Expression of needs often mainly towards caregivers
- Aggression, Autoaggression (esp in persons with ASS)
  - Lacking attachment to caregivers or disruption of daily structure leads to enhanced aggressive behaviour
  - Through aggression clients try to define their boundaries
  - Be aware that aggression often results from loss of control

Case example: Individuality of coping strategies

The caregiver dropped a client off at the train station, because the client wanted to visit her parents. Usually the client knew where to get off the train, but in this case she never reached her parents house. She took the wrong train and ended up in Bolzano (Italy) where she was asked to exit the train, since she had no valid ticket. The client stayed at the train station in Italy for two days and two nights. The police was alarmed and searched for her Europe-wide. They took her up and she was picked up by assistants of the caregiving organisation. The client never understood the seriousness of the situation. When asked what she had been doing at the train station the client stated that she got something to eat and then waited to be picked up by the caregivers. Afterwards the videos of security cameras were checked in order to make sure nobody took advantage of the client while she was at the train station.

The interviewed expert assumed that the client repressed the incident mentally since repression is the client's preferred strategy. For example, the client cuts people who passed away out of fotos and claims them to be non-existent.

Case example: Individuality of coping strategies

Another example is about a client, who collapsed and had a shoulder pain. The client had low pain sensitivity, which is why the caregiver drove him to the hospital. The doctor diagnosed a broken shoulder. The client had to stay at the hospital, because he needed surgery. To his disadvantage he collapsed a second time and broke the other shoulder. He then tried to push his self-esteem by claiming praise from the caregivers (encouraging them to tell him how brave he was).

Acute reactions/general observation

- Lack of communication and understanding as well as loss of control enhances stress reactions

  “Especially if needs can’t be expressed verbally but rather nonverbally. If clients do not feel well, they get irritated and confused behaviours are observable.”

Stress reactions/ persons with dementia

- Patient often feels threatened by emergency personnel
- Patient often refuses to go to hospital with them
- Patient sometimes cannot be talked to/no communication possible
- Emotional level active, no cognitive intervention possible
- No or reduced understandng of the situation

Stress reactions/persons with intellectual disability

- Reduced ability to verbally communicate emotional responses often leads to higher stress reaction
- If given a chance for information and understanding often very cooperative
- High dependence on caregivers
- Reactions may be delayed but merely the same as in individuals without impairment
- Stress reactions may last an extended period of time
- People with intellectual disability tend to use regressive coping strategies and more often show freezing and severe somatic reactions in acute situation

Needs/Intellectual disability

- Need for information: Difficulties in framing/understanding the critical event
- Need for social resources: Difficulties in using social resources
- Need for safety: After a loss persons with cognitive disability tend to interpret their environment as threatening, therefore establishing and keeping good structure is important

Needs/Intellectual disability

- Need for connectedness: Importance of persons of trust
- Need for control: There are many decisions that have to be taken, which put pressure on people with mental disability. Caregivers have to be aware of the individuals' need for regaining some control and responsibility

Needs/Dementia

- Need for safety
  Trust in helpers
- Need for calm
  Well structured environment: Knowledge and experience
- Need for connectedness
  Presence of trusted person/caregiver
- Need for self efficacy
  Adapting to person and his/her biography

Dealing with persons affected by dementia

- Assess indivudal needs and react accordingly
- Try to explain the situation
- Use emotional bond if existing
- Talking alone does not help use nonverbal communication
- Try to establish a relationship
- Use humour
- Well known caregivers and routines/places that are well known help to establish cooperation and communication
- Make contact via their worldview, know the clients biography

Dealing with persons affected by dementia

- Stay calm
- Provide a calm environment
- Re-Estabilsh and keep daily structure
- Put away certain things that may cause stress reactions
- Be aware of other patients reactions and needs, be aware of group effects/e.g. escalation of emotionality
- Keep emergency area closed

Grief reactions/persons with ID

- Understanding and being able to take part in mourning rituals helps the client
- If understanding and mourning is not possible, severe and prolonged grief reactions may follow

Case example

A client lost his brother. He died in an accident with a tractor. Two years before this event the clients sister died because of cancer. He dealt with those two losses very differently. The diagnosis of his sister initiated a process in which the client had the chance to prepare himself for his sister's death. After the sudden death of his brother, the client developed a depression. The caregivers tried to talk to him but without any success. Subsequently they decided to involve a psychiatrist who supported him with a pharmacological therapy, since he was behaving very regressively and not able to go to work.

Case example

A client who was not able to cope with the loss of her mother because she got no chance for mourning. The client was not properly informed about her mother's death and was neither allowed to attend the funeral nor participate in any other mourning rituals. Years later the client still showed clinically relevant reactions.

Case example

A clients aunt was diagnosed with cancer and told that she would die. The aunt was her closest attachment figure and the client visited her once every two weeks for the weekend, which was very important to the client. It was known that the client had problems dealing with loss and that she usually reacts in an emotional and aggressive way. The caregivers tried to prepare the client for the oncoming death of the aunt by talking about what might happen. Nevertheless there were emotional outbreaks and aggressive behavior like shouting and throwing things. The caregivers considered the outbreaks as “normal reactions of grieving” and tried to support the client as good as possible. It was known that praying was a strategy which helped the client to cope with the situation. So the caregivers and the client continuously prayed together, made a box with memories like fotos of the aunt and lighted candles. Moreover they supported the client at the aunt’s funeral. Shortly after the death of the aunt the client’s sister called, which was a surprise because there was no contact before. Consequently the sister offered that the client could visit her monthly for the weekend which helped the client to overcome her grief.

Grief/Intellectual impairment

- Discontinuous grief with good and bad phases
- Often delayed grief reactions
- Withdrawal and aggression as possible reactions
- Mourning rituals important for people with mental disability. Individual differences in the willingness to visit funeral services (autism spectrum disorders)
- Physiological reactions more common
- Return to everyday life is delayed, stepwise coping

Grief reactions/persons with ID

- Collective mourning rituals enhance the cohesion of the group (e.g. planting a tree)
- In the aftermath of a critical event, small changes are perceived as a “disaster”
- More intense lack of internal resources and future orientation compared to individuals without impairment
- Need for clients to understand and to process the loss
- Regression more prominent esp when understanding is not possible

Case example

20 years ago K. lost her sister due to cancer. Because of this traumatic experience she never visited a cemetery again and was extremely stressed by the topic of death and dying.

One and a half year later an inhabitant died due to a long disease. K. witnessed the development of the disease and was also present in the moment of death. Since this experience she. started to attend funerals again. Four months ago her father died. Her reaction in the process of grieving seemed to be normal.

There was a change in coping with death and loss. The caregivers concluded that following the process of the disease until the death of the inhabitant helped her in understanding the painful loss of her sister and supported her in overcoming her traumatic experience.

Grief reactions in persons with ID vs persons with ASD

- Be aware of differences in needs between people with autism spectrum disorders and persons with ID (mourning rituals and farewell not as important as well known structure- for example: everything shall be the same on mothers grave each time they visit, even small changes not tolerated)

Good practice recommendations by the experts

General recommendations

- Promote understanding and mourning: Degree to which awareness and understanding is possible and the possibility to make use of mourning rituals decide about the success of the grieving process
- Establish mourning rituals for those who profit from them, e.g. Planting a tree
- Invitation to talk
- Perpetuation of daily schedule: Daily schedule plays an important role in helping to cope

General Recommendations

- Present moment experience is especially important for people with mental disability
- Fulfilment of basic needs more important than crisis intervention
- Being acquainted with the client and knowing about their special needs is important to ensure adequate help
- Needs and decisions of clients play a mayor role and have to be respected

Specifics: Dealing with the affected person

- With Individuals who have a broader range of demands different senses are used in order to make them understand their daily structure
- Be aware that people who aren’t able to express their needs verbally have the same needs as the ones who are able to talk
- The closer the relationship towards the mentally disabled, the greater the possibility to fulfil the needs and individually support the affected

Specifics: Dealing with the affected person

- Be aware of the individual communication forms of each client
- Protect the clients from conflicts among or with the relatives (often relatives tend to overprotect the client and want to protect him/her from talking about the death/event and exclude them from mourning rituals)
- Observation and intervention needed for an extended period of time including intense work with relatives

Dealing with the affected person

- Contact external psychosocial health professionals to support grieving and fulfil the needs of the clients if necessary
- Time and compassion as important variables to support the positive transformation and acknowledge different needs
- In situations of grieving individuals with mental impairment should be encouraged to express their needs and special concerns
- Need to prepare if moving is necessary and at least keep persons of trust if possible

Good practice in interaction with relatives

Interaction with relatives

- Raising awareness as important tool to fulfil the needs of the client
- Often tense relationship between caregivers and relatives concerning the interpretation of grief reactions and degree of understanding in the client
- Be aware of clients needs towards family members
- Clients and relatives gain mutual understanding in the aftermath of bereavement

Interaction with relatives

- Acceptance of limits, e.g. unproductive cooperation with relatives , in this case focusing on the needs of the client
- Children with mental disabilities. Overprotection may be a problem
- Good cooperation between relatives and caregivers is important in order to exchange information on the clients condition in case of bereavement

Interaction with relatives

- Caregivers see themselves as professionals and parents see themselves as experts for their children-this might lead to conflicts
- Raising of awareness concerning the importance of understanding of death as important tool to overcome too much avoidance and overprotection

Parents needs

Case example

- A client lost his father. The client's mother decided to exclude him from the funeral because she feared that her son couldn't cope with the situation. The client himself was suffering badly because of the exclusion and had problems to keep the daily routine. Furthermore, he displayed noticeable behavioral problems at work.

Parents needs

- Parents often deny their child the possibility to take part in grieving
- Parents often try to protect their children from grieving
- Denial of taking part in grieving results in problematic behaviour at school
- Children with mental disability were seen as incompetent of understanding
- Parents of children with special needs have the same concerns and worries as other parents

Parents needs

- Parents aim to provide support and safety for their children
- Parents with mentally disabled children tend to experience worries to a higher degree
- Parents do not communicate the possibility of their own death, which aggravates the crisis in case of death
- Open or hidden appeal of the parents to intensify the care for the affected child
- Parents avoid to inform their children about death an the possibility to die even in case the client are grown- ups

What helps in dealing with the parents

- Supportive cooperation with parents, consent of clients and flexibility in time management contribute to an effective work
- Parents appreciation and interest for the needs of the child are important to deliver help
- Functioning cooperation among family and caregivers diminishes stress

What helps the caregivers

They are in a double role as affected and as professionals

- External counselling by professionals often seen as a as relief for caregivers
- Do not forget the needs of caregivers, e.g. Importance for caregivers to have their own mourning rituals for example carry the body of the deceased client
- Clear information dissemination and strategies throughout the whole organisation are crucial

Case example

A 43 –year- old man with a mental and physical disability fell from the couch during his lunchbreak sleep and had a strongly bleeding head wound. This never happened before and could not have been prevented. The caregiver informed the supervisor who also worked in the establishment. The supervisor alarmed the medical practicioner and shielded the area off to grant privacy to the client and to protect him and other inhabitants. The doctor sewed the laceration at the establishment, because the caregivers didn't want the client to go to the hospital alone and because the client would have been too stressed by leaving the facility together with people he did not know. The caregivers signed a form that they took over the decision to leave the client in the facility. The parents agreed to this decision.

The client recovered very quickly but there was a problem with the client's parents concerning the question of responsibility.

The parents first addressed the higher instance and thereby omitted the caregivers and the facility manager. In addition, one assistant felt extremely guilty because of the incident. The facility manager initiated a clarifying dialogue with the caregivers and the parents, which was very helpful for all persons involved.

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Prevention

Cooperation of all involved parties

- Good cooperation between relatives and professionals is essential
- Good cooperation between emergency personnel and caregivers
- Emergency personnel is supposed to gain an overview of existing resources and caregivers
- Importance for caregivers to communicate the constraints and needs of the client

Care for caregivers

- After emergencies in facilities for mentally disabled persons, a special focus should also be on the caregivers who always are in a double role, as a helper and as a person who has a close relationship with the client.

- Supervisors and managers have to take care of their personnel by providing adequate support.

Case example

A mentally disabled man of 30 years committed suicide. He lived in a room provided by the organization together with his also mentally disabled girlfriend. The client had a traumatic family history and had repeatedly been admitted to psychiatry as a teenager. In addition, he had a strong addiction to alcohol. Because of his addiction he tried a detoxification with the support of a medical therapy, which failed. In despite of the pharmaceuticals he continued to drink alcohol.

One morning the caregiver was wondering because he heard the alarm clock of the client not being turned of. The caregiver went in the room of the client and found him dead, lying in his bed. The autopsy showed that he took a pack of valium and rohypnol in combination with alcohol.

Case example

The caregiver was only a substitution, had no education in this field and only a few informations about the other clients. Nevertheless, he reacted quickly and informed the medical emergency service, his fellow workers and family members of the client. After the funeral the caregivers had to keep an eye on the dead clients girlfriend because she had problems to handle the situation and also tried to commit suicide by taking pills.

Prevention

- Documentation/emergency cards
  - Documentation and communication of basic information, medical data, upcoming doctor`s appointment and contact data of relatives
  - Communication and access to medical data of patients within a network (emergency workers, doctors, caregivers etc.) Treatment index cards
  - Interdisciplinary exchange between caregivers and emergency workers

Prevention/emergency plan

- Be prepared
- Create an emergency plan
- Have an idea of what to do in an emergency situation

Prevention/what to do

- Self-responsibility
- Helping each other
- Decide quickly what to do first in the current situation
- Be aware of your own limits
- Be able to bridge a certain time on your own

Disasters vs emergencies

- In disasters infrastructure does not longer exist, e. g. flooding
- The organizational structure for major events and disasters is predefined
- Have an evacuation plan and train regularly
- Have an emergency plan
- Prepare for evacuation for example by choosing another similar facility where clients may stay for some time if evacuation is necessary
- Invite members from emergency organisations to your facility and talk about disaster preparedness

Triage-classifications in disasters

I. Acute danger for life

II. Severe injury

III. Minor injury or no injury

IV. No or small chance of survival

V. Deceased

- According to these criteria transport and treatment priorities are decided
- Status of mental disability is not part of triage-system!!! Status of mental disability is of secondary importance at triage-system!!!

Resources caregivers/relatives

- https://www.cdc.gov/features/emergencypreparedness/

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