EUNAD HELPING THE DISABLED IN DISASTERS

universität innsbruck

Humanitarian Aid and Civil Protection

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

Information for first responders

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General Information

General/mental disabilities

- Same response and needs as individuals without impairment but reactions and emotions are more intense than in people without impairment
- Individuality of coping mechanisms

Intellectual disability

- Greater intensity of reactions and needs than in individuals without impairment
- Expression of needs often exclusively 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

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.”

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

Acute reactions/dementia

Cognitive reaction

- No or only limited understanding of the situation
- Instructions given from emergency worker can be followed only partially

Emotional reaction

- Desperation and helplessness
- Fear of emergency personnel
- Being overwhelmed
- Intense stress reactions

Acute reactions/dementia

- Behavioural reactions
  - Withdrawal
  - Trying to escape from situation (want to stand up and leave)
  - Refusing to go with emergency personnel (Hold on to the handrail or objects)
  - Controversial behavior (laughing instead of crying)Delayed reaction
  - Friendly behavior

Case example

A 70-year-old patient collapsed on account of pneumonia in her house. The patient was limited in her visual and hearing abilities and showed signs of the onset of dementia. The patient´s daughter informed the emergency service and accompanied the emergency doctor and the crew into the room of her mother. First the patient was confused about the new situation, so that the daughter had to explain it to her. This worked very well because daughter and mother had developed a special way of communication. With the help of the daughter the emergency doctor could provide medical care to the patient and give her medication via venous access on the forearm. Afterwards the patient had to be transported to the ambulance. This was difficult because the staircase was very narrow. The patient became nervous again due to the unusual situation and reacted against the transport. The emergency crew tried to calm down the patient, but it did not work, this is why they needed the help of the daughter once more. During the transport and also later in the hospital the daughter was still present, which made the whole procedure easier for the treating emergency doctor.

Interaction with the patient/dementia

- Use simple language
- Use Repetition
- Consider individual needs
- Use closeness and create safety
  - Hold the hand of the patient if he/she needs closeness
  - Stay with the patient
- Engage on the linguistic, visual, acoustic and cognitive level of the patient (simple language)
- Integrate reference person (relatives, caregiver) into the care of patient
- Integrate people with dementia into the grieving process of the whole family

Interaction with the patient/dementia

- Build trust
- Slow, calm and careful action
- Stay calm
- Patient and slow transfer to hospital staff
- Create calm and safe environment
- Create familiar environment
- Consider optimal patient care
- Guarantee privacy
- Involve reference persons if possible

Cooperation with reference person/dementia

- Integrate reference person (relatives, caregiver)
- Integrate reference person (relatives, caregiver) in care of patient (ambulance transport)
- Make use of the skills of the reference person (communication skills)

What is important/dementia

- Interdisciplinary exchange between caregiver, relatives and emergency workers
- Use patient´s reference person as informant and mediator, Integration of reference person (relatives, caregiver)
- Use reference person as support in communication
- Reference person gives safety and reassures the patient

Case example

A 85-year-old patient with dementia, who had fallen in the surroundings of her nursing home and had a bone fracture in the lower leg. She needed an operation. The accident occurred at 4 o'clock in the morning on a weekend. After admission to the accident and emergency department of the hospital, the treating anesthesist was called to carry out a preoperative evaluation of the patient. An anamnestic interview of the patient was not possible because of communication difficulties. Therefore the anesthesist had to consult the anamnesis of colleagues from the accident and emergency department. Existing nursing protocols from the nursing home of the patient were also consulted for the anamnesis. Afterwards the anaesthetist carried out the medical examination of the patient. Also this was difficult because the patient was primarily non responsive.

Case example

She seemed to be tired, confused and she could only mention her name and place of residence. Further communication about the circumstances of the accident was not possible. Altogether the patient was very restless and tried to get up over and over again. Instructions and explanations from the anaesthetist to stop this behaviour were unsuccessful. In an attempt to calm down the patient the anaesthetist took her hand, whereupon she calmed down immediately. After the preoperative evaluation was finished, the patient was brought to the OP. The change from known to unknown surroundings was extremely stressful for the patient, so she became nervous again. Due to this the planned anaesthesia seemed first not possible. Constant communication with the patient by the nurse made the anaesthesia finally possible and the operation could be started. To make the process of the operation more comfortable for the patient, a sedative co-drug was administered to her, whereupon she fell into a light twilight sleep. After the operation, the treatment of the patient was continued in the same style e. g. constant communication and touch and lots of patience

Prevention

- Practical training of evacuation
- Practical training of a triage
- Integration of the hospital staff in training of triage
- Integration of nursing home staff in practical trainings

Prevention

- IT-documentation of emergency accommodation and relevant contact persons in case of major events or disasters
- Make use of emergency cards

Resources EMS Dementia

- http://www.emdocs.net/dementia-emergency-department-can-anything/
- http://www.healthline.com/health-news/the-challenge-of-taking-someone-with-dementia-to-the-emergency-room
- https://www.hindawi.com/journals/ijad/2011/840312/

Acute reactions/intellectual disability

Emotional reactions

- Feelings of insecurity
- Fear because of information deficit about the medical procedure
- Freezing as common reaction
- Reaction depends on the kind of mental disability (Difference between down-syndrome or autism spectrum disorders)

Acute reactions/intellectual disability

Behavioural reactions

- Screaming, hyperactive and nervous behaviour
- Contraphobic and controversial behaviour: Curiosity, Interest, Moving towards the source of danger Emergency situation experienced as adventure
- Withdrawal
- Autoaggression/Aggression (Scratching, Biting) Aggressive reaction depends on the kind of mental disability

Acute reactions/intellectual disability

Behavioural reactions

- Showing extreme stress reactions (shock, screaming…)
- Open attitude towards unknown people (emergency workers)
- Positive attitude towards emergency workers (“The good ones”)
- In rare cases rejection

Case example

An intellectually and physically disabled boy of 15 fell down with his wheel chair in the elevator of a facility for disabled people. After that the door of the elevator could not be opened any more, so that the boy was caught in there all alone. It took a total of 1,5 hours until the boy was evacuated by the house technician and the fire brigade. The boy had fallen headlong over the wheel chair. He could not move because his feet were fixed at the wheel chair because of his spastic paralysis. After he was evacuated from the elevator, he was very nervous and screamed. Also the involved persons were very nervous because first they did not know whether he was seriously injured. When the emergency workers provided medical care to the boy, they found out that he only had a few abrasions and the nervousness of the caregiver team decreased. towards them.

Case example

With good coaxing from the caregivers and emergency workers the boy calmed down. Altogether the boy was very responsive and it was easy to talk with him. The caregivers used simple sentences to explain what happened to him, so that he understood the situation.

Overall the whole situation became very exciting for the boy and in the end he experienced it as an adventure. Also the transport to the hospital was uncomplicated because the boy was used to contact with emergency workers and basically showed a positive attitude towards them.

Interaction with the patient/intellectual disability

- Introduce yourself at the first contact with patient
- Engage individually with every patient
- Praise patient
- Encourage patient
- Adapt to the degree of mental disability
- Integrate mentally disabled people in the process of care

Interaction with the patient/intellectual disability

- Stay calm
- Use simple and playful words
- Use calm and understandable language
- Give clear instructions
- Give clear messages
- Communicate on the verbal or nonverbal level of the client
- Acceptance and respect towards client (do not treat adult person like a child)

Cooperation with reference person/intellectual disability

- Integrate relatives and caregivers in care of patient
- Reference person as help in communication
- Reference person should accompany the patient (e.g. ambulance transport)
- Introduce the reference person to the hospital staff
- Give clear and understandable instructions to relatives
- Distribute tasks to relatives
- Give information to relatives

Prevention

- IT-documentation of emergency accommodation and relevant contact persons in case of major events or disasters
- Make use of emergency cards

What is important/intellectual disability

- Open attitude of patient may be of use in establishing communication
- Integration of reference person (relatives, caregiver) in communication with patient
- Integration of reference person (relatives, caregiver) in care of patient
  - Relatives as information source
  - Advices from relatives for communication with patient
  - Relatives as support in communication with the patient
  - Relative as source of safety for patient

Prevention/intellectual disability

- Interdisciplinary exchange between caregivers and emergency workers
- Practical training of evacuation
- Practical training of triage
- Integration of hospital staff in training of triage
- Integration of caregivers in practical trainings

Resources EMS intellectual disability in emergencies

- http://www.intellectualdisability.info/how-to-guides/articles/guidelines-for-managing-the-patient-with-intellectual-disability-in-accident-and-emergency

Guidelines for AE

- Accept individuality
- Involve reference person
- Be aware of nonverbal behaviour
- Explain

Accept individuality

- Persons with intellectual disabilities vary greatly in their ability to understand and communicate their needs, discomforts and concerns.
- You will therefore need to adapt your approach to each patient's level of functioning and understanding

Involve reference person

- If the patient is behaving disruptively, begin by meeting briefly with the caregivers to inquire about the individual's level of functioning and to get advice about how best to meet and interact with the individual.
- Find out about any circumstances that might be specifically upsetting for that individual (e.g., being asked too many questions; being in a noisy/busy environment; someone moving too close to them; seeing reflecting surfaces, such as eyeglasses).

Be aware of nonverbal behaviours

- Many individuals may be unable to communicate verbally but will be aware of non-verbal behaviours in others and are often sensitized to negative attitudes others have toward them.
- Some individuals depend on others to help modulate their emotions and will quickly pick up fear and anxiety in you.
- A warm, accepting, calm and reassuring attitude will help the patient feel more relaxed.

Explain

- A&E is generally a strange and unfamiliar environment for anyone. For persons with intellectual disabilities, the experience may be particularly scary because they may not understand what is happening around them.
- Getting to A&E may also have been traumatic, both for the patient and his or her family.
- Waiting can be anxiety-provoking and contribute to behavioural disturbances. Take a moment to explain to the patient and his or her caregivers the reason for the wait. If the wait is longer than you expected, check in from time to time to reassure the patient. This will contribute to a more effective interview.

Involve caregivers/relatives

- Remember that persons with intellectual disabilities have a variable and limited ability to interpret their own internal cues and may not be able to give you an accurate picture of their internal state.
- Involving caregivers who know the individual well may help you to better understand his or her subjective experiences.

Tipps for medical interview

- Try to make the individual as comfortable as possible.
- Familiarity helps. Suggest that someone familiar to the patient (e.g., caregiver) remains present
- Use suggestions previously identified by the caregiver to help the patient be more at ease.
- Encourage use of "comforters" (e.g., Does the individual have a favourite item he or she likes to carry or does the patient like to engage in self-soothing, such as rocking or standing?).
- Try to find a quiet spot, without interruptions.

Tipps for medical interview

Try to establish a positive relationship with the patient: Find ways to communicate effectively:

- Use simple words
- Speak slowly
- Do not shout
- Pause. Do not overload the individual with words

Tipps for medical interview

- Be sensitive to the individual's nonverbal cues and adjust your behaviour accordingly. For example, if the patient shows fear in response to your approach, consider what might be contributing to this fear (e.g., reflection from your eyeglasses, white coat, stethoscope) before approaching further.
- Modify your approach as required (e.g., take off white coat, enlist the participation of familiar caregiver).
  - Use visuals (e.g., drawings)
  - Use gestures

Autism spectrum disorders

- https://www.autismspeaks.org/family-services/autism-safety-project/first-responders/emergency-services

Autism spectrum disorders

Rzucidlo, S.F. (2007). Autism 101 for EMS, from SPEAK Web site: www.papremisealert.com

- Some individuals with autism do not have a normal range of sensations and may not feel the cold, heat, or pain in a typical manner. In fact they may fail to acknowledge pain in spite of significant pathology being present. They may show an unusual pain response that could include laughter, humming, singing and removing of clothing.
- Individuals with autism often have tactile sensory issues. Band-aids or other adhesive products could increase anxiety and aggression.

Autism spectrum disorders

Rzucidlo, S.F. (2007). Autism 101 for EMS, from SPEAK Web site: www.papremisealert.com

- Avoid sudden movements.
- Move slowly, performing exams distal to proximal.
- Explain what you plan to do in advance and as you do it. Explain where you are going and what they may see and who might be there. This may avert unnecessary anxiety and/or outbursts of aggression from the patient. Individuals who appear not to understand may have better receptive language, which may not always be entirely evident.
- Expect the unexpected. Clients with autism may ingest something or get into something without their caregivers realizing it. Look for less obvious causality and inspect carefully for other injuries.

Autism spectrum disorders

Rzucidlo, S.F. (2007). Autism 101 for EMS, from SPEAK Web site: www.papremisealert.com

- If possible ask a caregiver what the functional level of the individual with autism is, then treat accordingly. Stickers, stuffed animals and such which are used to calm young children may be helpful even in older patients.
- Attempt to perform exams in a quiet spot if at all possible, depending on the severity of injury and safety of the scene. Demonstrating what the exam will consist of on another person first may help the person with autism have a visual knowledge of what your intentions are.

Resources for EMS

- http://papremisealert.com/us/autism-101-for-fire-rescue/
- https://www.autismspeaks.org/family-services/autism-safety-project/first-responders/emergency-services
- http://www.post-gazette.com/health/2012/06/18/Treating-autism-patients-in-emergencies-presents-challenges/stories/201206180131#ixzz1yHIpJtiD
- https://www.cdc.gov/features/emergencypreparedness/