Severe Dual Sensory Losses in Old age, or Deafblindness among the Old

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Experiences from a Norwegian Study (Lyng and Svingen, 2001-2003)

The Nordic Definition of Deafblindness

- **Deafblindness**
  - Deafblindness is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, deafblindness is a distinct disability.
- **Main implications**
  - To varying degrees, deafblindness limits activities and restricts full participation in society. It affects social life, communication, access to information, orientation and the ability to move around freely and safely.
  - To help compensate for the combined vision and hearing impairment, especially the tactile sense becomes important.

- You might have Dual Sensory Losses without being deafblind

Using the Nordic Definition

- To find old people with Deafblindness but naming them otherwise
- To find people with Severe Dual Sensory Losses (SDSL) that are Deafblind

Identification of SDSL in old age

- Identify populations with expected high frequency of SDSL
- Screening based on observation of typical functional difficulties
- Self report on own vision and hearing
- Functional assesment interview by DB-expert
- Objective assessment

The SDSL screen

- Checklist
  - 7 questions about practical consequences of severe visual impairment
  - 7 questions about practical consequences of severe hearing impairment
- Self-evaluation of visual and auditory function

Checklist and questionnaire addresses function in context

- Typical manifest problems in ADL
- Communication (different conditions)
- Access to information (visual, auditive and tactile).
- Orientation and mobility(indoors and outdoors, travelling).
- Activities of Daily Living.

Screening questions

- Example Vision:

  “You are not recognized when you visit unexpectedly (problems recognizing faces at distance)”

- Example Hearing:

  “He/she does not hear you when you knock on the door or ring the doorbell”.

- Subjective assessment

  How do you rate the quality of your vision/hearing compared to other persons of your own age?

  (Alt: Good, fair, poor, very poor)

Psychometric properties of SDSL screen

Criteria: Two simultaneous checks for both vision and hearing and evaluates own vision and hearing as fair, poor or very poor.

- Sensitivity: 97%
- Specificity: 39%
- Positive predictive value: 74%
- False positives: 61%
- False negatives: 3%

Who are the Deafblind Old in Norway according to the Nordic Definition of DB and identified by the SDSL screen?

- SDSL population is old and frail (mean age 89 years)
- Have had their sensory loses for 20-30 years
- Counts about 5% of the population over 80
- Majority, 75%, with SDSL (in Norway) live at home
- Vision problems are more pronounced in the SDSL group and the major causes are retinal diseases (macular degeneration, glaucoma) and the changes in the lens (cataract) Degenerative
- Hearing problems are shared with adults without SDSL and is age related (presbyacusis) Degenerative
- Needs assistance from many sources, public services is not sufficient
- Not satisfied with technical aids

Rehabilitation

- Interventions works. 80 % satisfied
- Time consuming, in particular the assessment work
- Important to replace ageing as a overall explanation with a concrete functional analysis
- To reconnect life history and activity with present situation

Quantitative measures

- In our study the Nordic definition corresponded more or less with a cut-off score of VA ≤.3 and HL ≥40 dB
- But also individuals with DB outside this area

Are the Old Adults with Severe Dual Sensory problems Deafblind?

- Yes: Deafblind according to functional definition of the Nordic Definition
- As a group they are different from the “classical” congenital group in their culture, language and experiences
- Interventions towards the group based on experiences and knowledge from the work with the congenital deafblind are successful
- If asked the person would reject she was deafblind

The Gold Standard for DB identification in Old Adults

- Should be based on the Nordic functional definition
- Observes sensory function in context and as component in a functional system
- It focuses on- and identifies the functional problems that needs to be addressed in the rehabilitation process

Challenges

- Earlier identification
  - GPs
  - Centers for the Elderly
- Cooperation- and cross-referrals between specialits
  - Monitor individuals with AMD for presbyacusis
  - Monitor hearing impared for retinal problems
- Defeat the assumption that all changes in old age is a direct result of biology
- Improve knowledge about age-related sensory problems in care and among the public
- Follow up from competence system

Deafblindness in a functional dynamic perspective

- As a developmental issue (classical)
  - Setting up an alternative sign system to spoken or visual language for communication and acquisition of cultural tools and culture. Developing a cognitive system
- As an old age issue (also developmental?)
  - Reorganizing adaptive functional systems by substituting failing sensory inputs with alternative input system. Relies heavily on cognitive components

Interventions in Classical DB

- Establish mediational tools though the acquisition a sign system through signs based on tactile and other senses compensating for the non-functional vision and hearing
- Establish and build shared meaning and access to society and culture
- Become a human being

Interventions in SDSL

- Reconnect and renegotiate life history and activities under changed conditions
- Reconstruct, reorganize functional system with alternative components
- Gradually deteriorated automatized function makes it easier to adapt to
- A particular role in the availability of mediational tools through the cognitive apparatus
- Higher level systems can compensate for deteriorated functional components at lower levels

The SDSL group and the Competence system for the Deafblind

- Too large group to receive direct consultation
  - About 5000 at 5% prevalence 2025
- Should be part of the identification process
- Consult primary health services in building the services for the SDSL at municipal level