

Ageing with severe dual sensory loss.

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Introduction

The vision and hearing difficulties that underlie severe dual sensory loss (SDSL) are progressive in most cases. The incidence of the condition increases with age and especially from the end of the 70s. Combined severe vision- and hearing difficulties in old age lead to severe functional limitations in various areas of daily life, primarily the ability to communicate under different conditions, acquire information, mobility and carry out practical tasks. The functional difficulties easily lead to severe social isolation. The purpose of this project has been to uncover the variations in SDSL, the consequences this type of sensory loss has for quality of life, and how they can be managed. We also wanted to investigate whether rehabilitative interventions aimed at vision and hearing can improve functional ability and quality of life in the group. It has been a goal to develop a model for identification, assessment and intervention for old adults with SDSL.

Metode

The participants in this project were recruited from 4 municipalities in Norway distributed among the 4 regional competence centers for the deafblind in Norway. Except for two individuals, all participants were identified using a checklist-based screening method. The checklist consisted of 7 questions about behavioral characteristics typical of severe visual impairments and a corresponding number for severe hearing impairments. People with markings for both vision and hearing difficulties defined the target group. The screening was carried out by staff in the long-term care for the elderly (LTE) in the individual municipality. A total of 2,553 people over the age of 67 who were users of LTE in the relevant municipalities were examined with the checklist and a total of 102 people were found to have signs of both vision and hearing difficulties. Of these, 31 people said they were willing to participate in the intervention study. After a thorough clinical assessment, 25 of these are considered to have SDSL. Seven people died during the duration of the project.

The interventions were based on a comprehensive survey of resources, interests and needs. Functional areas related to the sensory loss such as communication, mobility and information were assessed based on the person's own assessments of function and ability, their subjective meaning, and the desire for change. Depending on personal preferences, type and degree of the sensory loss, various types of individually targeted interventions were tried out with the aim of optimizing the use of vision and hearing and/or measures of a compensatory nature. The interventions aimed at the local environment aimed to improve the conditions for function and satisfaction. These included changes in the daily, physical environment, and information and training of staff and significant people. The assessment often went over 3-4 sessions with conversations to clarify interests and needs. It was the participants' own perception of the desired change that was decisive for the choice of measures. The interventions were corrected at follow-up visits at approximately 3-month intervals. Mapping and interventions were mainly carried out in collaboration with the ordinary support system. The key role in this work was played by the

deafblind consultant in the regional competence system for the deafblind. The evaluation of the measures was based on observation of whether the measure in question had been carried out and changes in functional ability and the person's own satisfaction with the change.

In addition, a questionnaire survey was carried out among a random sample of people over the age of 67 in the relevant municipalities (n=425) in which they were asked for subjective assessments of e.g. health, sight and hearing, ADL - functions and social relations. This group serves as a reference group (R) for the group with SDSL.

Results

The SDSL group was on average 89 years old and 13 years older than the reference group. Most lived at home (68%). The SDSL group does not differ from the reference group in demographic characteristics other than age and marital status when correcting for the age difference. In the assessment of their own health, the KAS group distinguished themselves in characterizing their health as weaker than the reference group, an effect that also holds when we adjust for the effect of age. The group had less social interaction outside the home than the reference group but received the same number of visits. All in the KAS group depended on help from family, friends, or neighbors to cope with everyday life in addition to the regular municipal services they received.

While the vision difficulties in the group with KAS were primarily associated with age-related diseases of the eye (senile macular degeneration, cataracts, and glaucoma), the hearing difficulties were associated with the typical age-related hearing loss, presbycusis. The perceived hearing difficulties were largely the same for the two groups, while the assessments of the visual difficulties showed far greater subjective difficulties in the SDSL group (also when we correct for the effect of age). It is therefore the visual difficulties that contribute to the biggest behavior-related difficulties, i.e. in ADL skills.

A total of 73 individual interventions were carried out across 7 different domains for the 25 participants. Most of the interventions related to communication and information access. On average, 3 interventions were carried out per person. Number of interventions per person ranged from 1 to 5.

The evaluations showed that these interventions were successful in 80% of the cases, as the participants felt that the function had improved and that they themselves were more satisfied. Where the interventions have not led to satisfactory changes, this was mainly due to miscommunication and/or faulty technical aids, and/or major health changes in the participants with impact on general functional ability.

Conclusions

The group of old adults who have been identified with severe dual sensory loss (SDSL) in this project are very old with significant comorbidity. Because the medical conditions underlying the sensory loss are progressive, the condition should possibly be identified and intervened towards earlier. However, this presupposes that cross-checks of vision and hearing are done when examining one of the senses and referred across specialties. Here, general practitioners and vision and hearing specialists can play an important role. Identification based exclusively on care and care services in the municipality will automatically capture the

old-old adults. Early identification will be crucial to take adequate measures that can limit the consequences of sensory loss.

Interventions to improve the functional ability of older people with SDSL have a good effect on functional ability and quality of life. Almost all measures that were put in place were successful because the function was improved, and the users were more satisfied. This effect was persistent. However, the rehabilitation process was very time-consuming for both user and carer. In addition, it is complex because of the high comorbidity in the group. We consider a comprehensive function and needs survey to be fundamental to a successful rehabilitation process. This must be based on the individual's own assessments of function and skill, and the subjective importance of different functional domains as well as the desire for change. Another prerequisite is that the process is based on the individual's own needs and choices.

An important part of the rehabilitation process is associated with selection, adaptation, and training in the use of aids. Existing aids for sight and hearing generally show satisfactory results also for older people with SDSL. Because these in general are adapted to unimodal sensory loss, they will not always be well adapted to SDSL, as the aids usually require an intact compensatory sense.

When vision- and hearing difficulties occur in combination; for our target group also in connection with other functional difficulties, several professional bodies and actors are involved in the rehabilitation service. A lack of expertise about sensory loss in general and severe dual loss in particular means that users' needs are often not taken care of in a satisfactory way. Hence, there is a need for increased knowledge about sensory loss among old adults. This also includes knowledge about aids, their use and function, and how the environment can be adapted. Building design and designing environments must also be included here.

There is also a need to develop good and effective collaboration routines and to coordinate the efforts of the many groups and organizations involved in the rehabilitation process.

This study has included a small number of old adults with SDSL from 4 different Norwegian municipalities. All were recruited via LTE in the municipality. The fact that most users of LTE are over 80 partly explains the high average age among the participants. A sparse literature suggests that SDSL has a low incidence before the age of 80. Nevertheless, the condition could be identified earlier since most conditions that lead to KAS are progressive. This implies a different identification strategy than the one used in this project. A strategy aimed at general practitioners, seniors' centers and other bodies could provide better opportunities to catch this group earlier. An earlier identification could provide better access to resources for the person in a rehabilitation process.

Although the quality of life in this study is not measured by standardized scales, we consider the measures used valid because they provide direct statements of subjective well-being in areas that the person holds important to themselves, as well as an expressed desire for change in that particular area. The person's own assessment of satisfaction with interventions based on this type of choice will reflect quality of life.