Abstract

Visual impairments (VI) burden particularly the aging population globally. In order to ensure healthy aging despite disability, the health care systems must provide effective low vision rehabilitation services (LVR) for those in need. Low vision rehabilitation counselling (LVRC) requires specialized multidisciplinary teamwork and has not been studied in detail among the elderly. This study aims to provide a comprehensive picture of individual LVRC actions and introduce a LVRC classification to use for attempts to improve the LVRC processes. The present study employed a qualitative follow-up design. Data describing the individual LVRC processes in a prospective cohort of elderly patients with VI (n=39) were collected individually over two years during the years 2016-2019. The data were analyzed through deductive content analysis. The analyzed LVRC provided assistive devices, services and home modifications, but problems related to independent movement in the living environment, psychosocial burdens, adaptation to disability and learning new compensatory skills received less attention. To ensure effective LVRC, the multiprofessional team providing the rehabilitation should emphasize goal setting and continuous assessment. LVRC should be seen as a process of adaptation, adherence and learning. LVRC should support and promote older adults to participate and function to their full potential in the modern society, which includes utilizing digital technologies.

Keywords:

visual impairment, low vision rehabilitation, rehabilitation counselling, older adult,

content analysis

Introduction

Global population aging has been strongly linked to the worldwide epidemic of chronic and degenerative diseases (Prince et al,. 2015). Visual impairment (VI) among the elderly might be perceived as a marginal phenomenon by some, but in fact, VI affects the aging population to the same extent as Alzheimer's disease (WHO, 2011). The burden of VI arises from disability rather than mortality; therefore, this condition is associated with considerable societal and individual costs (Prince et al., 2015).

VI refers to a disability in which the visual acuity (VA) of the better-seeing eye is <0.3 despite corrective lenses (glasses), or the visual field has narrowed to <20 degrees (radius) permanently (Meyniel, Bodaghi & Robet, 2017; WHO, 2019). Moderate and severe VI is especially common in women in and over their 50s age-related macular degeneration (AMD) being the most common disease causing VI (Flaxman et al., 2017; Bourne et al., 2017). It should also be noted that the prevalence of AMD increases rapidly after a person reaches the age of 75 (Wong et al., 2014). This calls for attention and effective actions by eye health care and rehabilitation to meet the growing needs of aging populations to pursue the goal of healthy aging (GBD 2019 Blindness and Vision Impairment Collaborators on the behalf of the Vision Loss Expert Group of the Global

Burden of Disease Study, 2021). Sufficient services are needed both to prevent vision loss in the first place, and to help those who permanently lose vision. (WHO, 2019.) Visual impairment may affect individuals in various ways, yet the most common negative impact is the decreased ability to perform vision-related tasks of personal and instrumental daily activities (Meyniel et al,. 2017). As such, the need for low vision rehabilitation (LVR) has increased in recent years (Trauzettel-Klosinski, 2011), both as a result of a growing older population and elderly patients' expectations that they will be able to independently care for themselves.

Rehabilitation is a complex process that can occur in countless environments depending on whether multidisciplinary teams and specialist expertise is involved (Wade, 2020). An evidence-based description of effective rehabilitation includes aspects of problemsolving, holistic biopsychosocial care and a person-centered approach (Wade, 2020). Modern LVR is a multidisciplinary professional service that aims at optimal use of residual visual function, training of new skills and re-integration in society (Markowitz, 2016). In Finland, LVR and LVRC is provided within specialized healthcare (eye hospital) and a multi-professional team. An ophthalmologist, an optometrist, a social worker and rehabilitation counsellor(s) responsible for counselling and guidance in orientation and mobility training, daily life activities training as well as visual skills rehabilitation and assistive devices may all be included in the multiprofessional team. The expertise of an occupational therapist could strengthen a multi-professional team, but this is not common in Finland.

Research related to LVR is valuable and urgently needed, as there is currently limited evidence on the effectiveness and benefits of LVR (Trauzetter-Klosinski, 2011; van Nispen et al., 2020). There is some evidence that LVR positively affects clinical and functional ability outcomes, especially reading ability, but further research is needed to determine whether these results extend outside of a controlled testing environment. The effects of LVR on mood, quality of life (QoL) and HRQoL are less clear and there is currently only limited evidence on the cost-effectiveness of LVR. Moreover, several studies have reported encouraging results from group interventions, but more research is needed on home-based LVR and how rehabilitation outcomes change over time. (Binns et al., 2012.)

This study, which complements the findings of previous literature by adopting a practical nursing science and rehabilitation counselling perspective on LVR, applied a qualitative follow-up study design to investigate the typical characteristics of multidisciplinary LVR and LVRC provided in Finland, northern Europe. The study was

performed because no similar follow-up study has been conducted on a national or international level among older people with visual impairments.

This study aims to provide a comprehensive picture of individual LVRC actions, and introduces a classification for LVRC that can be used to develop rehabilitation processes that better meet the needs of older adults with VI. Following research question was addressed: Based on patient records made by LVRC professionals, what did individual LVRC provided over two years entail for older adults?

Methods

The present study is part of a larger mixed-methods follow-up study aiming to describe the HRQoL of VI older adults and their individual LVR processes (Siira, 2021). The study included older adults from a hospital district in northern Finland. The inclusion criteria were: age ≥ 65 years; living at home; moderate or severe visual impairment according to WHO definitions (2003); and no previous history of receiving LVR services. The sample consisted of elderly VI patients who had been referred to LVR services at Oulu Low Vision Center (OLVC) between May 2016 and May 2017. At the start of the study, 39 older adults provided informed consent to participate, while 28 participants took part in the two-year follow-up.

Research data for this study, which comprised descriptions of the process and content of individual LVRC, were gathered from patient records that detailed the onset of the individual LVRC process and continued until the rehabilitation had lasted up to two years (24 months). The collected data were first tabulated to get an overview. Entries and notes were made to the material. The raw data consisted of 38 pages of written, single-spaced material in 8-point font. The data analysis employed content analysis and applied a deductive approach (Kyngäs & Kaakinen, 2020). The starting point for analysis was the multidisciplinary LVRC provided for older adults by specialized

healthcare as clinical rehabilitation and descriptions of LVRC identified in the patient records. The multidisciplinary team responsible for LVRC in OLVC included an ophthalmologist, a low vision instructor, low vision rehabilitation counsellors and an optician. The information they produced on LVRC processes was interpreted as a whole. Meaning was selected as the unit of analysis. (Kyngäs & Kaakinen, 2020.)

In the deductive analysis to answer the research question, the National Classification of Rehabilitation Counselling provided by The Association of Finnish Municipalities (AFM 2020), was used as a theoretical structure and matrix for analysis according to Kyngäs & Kaakinen (2020). National Classification of Rehabilitation Counselling is used for documenting and structuring the patient records in electronic patient record systems for rehabilitation counseling in clinical rehabilitation settings in Finland in order to unify the concepts and terms of rehabilitation counselling. This analysis matrix was translated into English by the first author with permission from the AFM (personal communication by e-mail 15.4.2020) and is presented in detail in Table 1. The classification consists of five-character codes: a pair of letters followed by three numbers. "R" refers to rehabilitation and "K" to rehabilitation counselling. The classification has nine thematic main categories, which are divided into the subcategories presented in Table 1. Thematically, the sections include activities related to examination and assessment, guidance and therapy practices, support for living and

work, and other similar activities. In addition to functions that are directly targeted at the customer, the classification also includes sections related to indirect work and administrative activities, e.g., data acquisition and documentation, as well as expert, training and education and developmental tasks. All instances related to research question were identified, recorded into the matrix and quantified based on how many times the content appeared in the material; the total number of appearances on both the thematic main category (=N) and subcategory (=n) levels are shown.

The study was conducted in accordance with the principles of good scientific practice and responsible conduct of research and procedures (TENK, 2012; WMA, 2017). An appropriate research permit from the Northern Ostrobothnia Hospital District and an affirmative statement of the Regional Ethics Committee (number 36/2016) were obtained. Research data were processed with Microsoft Word® software (Microsoft Corporation, Redmond, WA, USA).

Results

The participants of the study (n=39) were dispersed around the hospital district, with a mean distance of 63 km from their home to the OLVC. The longest distance to OLVC services was from the eastern periphery of the hospital district (217km). The participants represented older adults between 72 to 95 years of age at the completion of the two-year follow-up period, with a mean age of 84 years. The vast majority of the subjects was women (n=27), and visual impairment was caused by age-related macular degeneration or other retinal disease (n=33) in most cases. The majority of the participants had moderate VI (n=34) according to the WHO classification. Other diseases and health conditions were not systematically examined. However, the analyzed records mentioned that due to memory loss, two participants may only experience limited benefits from the assistive devices, while it was specified that six of the participants also had hearing impairments.

Individual LVRC processes

There were a total of 132 individual LVRC sessions over the two-year study period. Over half of the sessions represented an outpatient visit to the OLVC (n=75; 57%), while 30% (n=40) of the sessions were in the form of a home visit by a LVR counsellor. Only a small fraction (n=12; 9%) of the LVRC sessions documented in the patient records were performed via telephone. In one instance, LVRC was provided in conjunction with another hospital visit, while a handful (n=4; 10%) of the subjects attended a three-day adaptation training. The number of LVRC sessions during the two-year study period ranged from a minimum of the initial session to a maximum of eight sessions, with the mean number of sessions between 3-4.

The 523 LVRC interventions recognized from the study material are presented in detail in Table 1. Most of the LVRC interventions focused on *Activities supporting survival in the living environment* (RK3, N=299), with the most common LVRC actions under this category of rehabilitation counselling including *Services related to assistive devices*, *Review of the situation and assessment of the need for assistive devices*, *Acquisition*, *borrowing and handing over assistive devices*, and *Guidance and monitoring of the use of assistive devices* (from RK320 to RK324, n=232). *Guidance and counselling supporting rehabilitation* (RK2, N=117) was another category of rehabilitation counselling that was well represented in the study material, with most of the LVRC actions falling under *Guidance and counselling related to services and support* (RK220, n=40), *Guidance and counselling related to disability services* (RK222, n=14), *Guidance and counselling related to the activities of communities and third sector organizations* (RK224, n=21), and *Guidance and counselling related to hobbies and leisure activities* (RK225, n=19). *Assessment and planning in rehabilitation counselling* (RK1, N=69) predominantly comprised the actions of *Investigating and assessing the client's situation* (RK110, n=28) and *Assessment of the overall situation* (RK111, n=16).The analyzed LVRC interventions included very few instances of *Tasks related to coordination and co-operation* (RK4, N=8), while *Other additional activities connected to client services in rehabilitation counselling* (RK5, N=30) mainly comprised *Statements prepared by the rehabilitation counsellor* (RK530, n=18).

[Insert table 1]

Discussion

This study described chronicles individual LVRC processes and interventions. Based on the results, the normal LVRC process could be improved to better meet the needs of older adults with VI, as well as support their functioning, quality of life, successful aging and integration into modern digital society. The results also provide a hint of the costs associated with VI among the elderly since the costs of LVRC for the cohort in question can be counted and the information used in the evaluation and development of LVR services at organizational level.

Based on the analyzed records, the study participants received unique and personal LVRC services, which agrees with Wade's (2020) recommendations that rehabilitation has to be highly individual and person-centered. The LVR provided over the two-year study period represented the introduced classification of rehabilitation counselling (AFM, 2020) rather well. LVR provided took into account many of the everyday challenges posed by low vision and visual impairments by meeting them through the introduction of assistive devices, counselling services or modifications to the home environment. Nevertheless, certain aspects were taken less into consideration than others. Problems related to independent movement in the living environment, VI-related

psychosocial burdens, adaptation to disability and learning new compensatory skills at old age received less attention. Similar findings of service provision not fully meeting older adults' needs for cognitive, emotional and practical support due to VI have been reported previously by Standford et al. (2009).

The results highlight, in accordance with previous literature (Sgaramelli et al., 2017), that professionals involved in LVRC need to reinforce adaptation to disability, learning compensatory skills and participation in rehabilitation among older patients, as surprisingly few of the participants in this study took part in the offered adaptation training. These types of interventions could be beneficial because they target aspects of rehabilitation that – based on the current analysis – seem to be lacking. These aspects include adapting to disability, psychosocial and peer support, building knowledge and discussions. According to Wade (2020), self-management with a long-term disability depends on education. The results of this study suggest that a stronger focus on patient education could improve LVRC. Beneficial patient education should explain how the disease causes disability, present skills related to self-management, and provide psychosocial and emotional support (Wade, 2020). Perhaps adaptation training that utilizes digital solutions could be offered as an alternative implementation in the near future.

As the ultimate goal of LVR should be promoting QoL and optimal functioning in society (Colenbrander & Fletcher, 2018), LVR should focus on individual goal-setting along with the regular structured evaluation of LVR processes. Wade (2020) found that a universal problem with rehabilitation is that patients do not know what to expect and how to set goals. This study suggests that individual assessment and goal setting could concretize LVR activities by providing an overview of the entire process. Selecting instruments based on the widely accepted International Classification of Functioning, Disability and Health (ICF) from WHO (Kostanjsek, 2011) for assessment and continuous evaluation could transform LVR from a process of knowledge-based practices to a transparent and integrated procedure that considers diverse aspects of functioning. McDougall et al. (2011) also note the usefulness of ICF framework in exploring the complex phenomena of functioning and its relation to individuals' with chronic conditions on perceptions of their quality of life.

The results of this study suggest that certain older adults find it difficult to adhere to LVRC and might not have the knowledge, skills or resources to proactively participate in the rehabilitation process. LVR patients must adopt an independent, self-directed and proactive role in the rehabilitation process, which may be difficult for many older people. This finding is in accordance with Haanes & Eilertsen (2019) who state that the oldest old might not have the strength or willingness to rehabilitation actions for sensory

impairments due to more serious health issues affecting they are struggling with. Still, LVR professionals should use validated questionnaires to assess adherence (E et al., 2020) and identify ways to facilitate adherence, at least closely monitor and apply assistance for those in danger of inactivity (Haanes & Eilertsen, 2019).

The study material revealed that many of the participants commonly experienced problems reading (with or without visual aids). Interestingly, participants still had problems even if the visual aids had been presented well. A selective review of randomized controlled trials in the field of visual rehabilitation by Trauzettel-Klosinski (2011) suggested that specific training to improve reading speed could be beneficial. In addition to specialist care and healthcare professionals, such as group training could be organized by, for example, an organization for the visually impaired. On the other hand, LVR also includes aspects of educational gerontology and patient education. As such, LVR professionals need to have pedagogical competence in order to effectively teach older patients new skills, such as the use of residual vision and assistive devices. This is an area that needs further research attention.

Trustworthiness and limitations of the study

The trustworthiness of this study can be evaluated through the criteria of credibility, transferability, dependability, confirmability and authenticity (Elo et al., 2014; Kyngäs, Kääriäinen & Elo, 2020).

Using the National Classification of Rehabilitation Counselling as an analysis matrix increased the credibility of our results. The classification is used to describe the implementation, content and functions of rehabilitation work, and although developed in Finland, could also be applied in different international contexts. There is room for discussion as to how the researcher interpreted LVRC with the analysis matrix. The credibility of the study is reinforced by the fact that the researcher is familiar with the content and practices of LVRC, as well as the classification of rehabilitation counselling, having worked as a rehabilitation counsellor and providing LVRC services to older adults over many years. Therefore, it can be assumed that the researcher was able to interpret the data from patient records with sufficient credibility. The researcher was not involved in the LVRC of the study participants at any time during the two-year follow-up, and could not have influenced the research data, which represented patient records produced by others. Nevertheless, it should be stated that the researcher had individual contact with all of the participants of patient data for gravitic participants of the study the stated that the researcher had individual contact with all of the participants on four distinct occasions throughout the

follow-up period, which provided certain knowledge that may not have been attained by only analyzing the patient records and, as such, could have influenced the data interpretation. However, this issue could have increased the reliability of the results since the researcher had a broader picture of LVRC based on knowledge of patients' real-life situations. The researcher's experience in the field of LVRC strongly influenced the research process, formulation of the research question, data collection design and choice of methods for data analysis. While the researcher's prior experience and knowledge of LVRC may have influenced the data interpretation, strict adherence to ethical principles throughout the study increased the credibility of the presented results. To increase the confirmability of the inductive content analysis, the patient records were carefully read through several times to get an overview of the situation. Notes and entries were then made to the study material to organize data, after which inductive content analysis followed the suggested steps. , namely, simplification of expressions, including similar expressions in specific subcategories, and then organizing similar subcategories in upper categories. The transparency, consistency and confirmability of inductive content analysis process is presented in Figure 2. Original quotations, translated from the original Finnish, are provided in the text to ensure dependability and authenticity.

When discussing the dependability of the current study and results, it is notable that the individual LVRC processes continued after the follow-up period (24 months) ended. Therefore, certain important and relevant activities may have occurred after the follow-up period ended and are not reflected in the current results. Nevertheless, the multiprofessional team that provided the LVRC services examined in this study has decades of experience in LVRC, and the study included numerous participants, so it can be assumed that the results are stable over time, which increases the dependability of the study.

The performed two-year follow-up study of older adults with VI is unique both nationally and internationally as it improves the transparency of rehabilitation processes of the visually impaired older adults. The rather small sample size is a limitation, but the longitudinal and qualitative approach was able to achieve data saturation, as well as provide a rich evidence base from which to draw conclusions that add to existing knowledge about LVRC. The results are internationally relevant since LVR actions are similar across the multiprofessional healthcare settings of modern societies. As van Nispen et al. (2020) also suggest future research should investigate the effectiveness and meaningfulness of LVR processes in more detail. This would require interventional studies that also apply a qualitative approach to explore the diversity of experiences in

relation to severity of VI. A closer look at the cost-effectiveness of LVR, which could include quality- adjusted life years, should also be a priority for future research.

Conclusion

Based on the results of this study, LVR should be systematically planned, closely monitored and continually evaluated with validated instruments to effectively and meaningfully support independent, active and successful aging despite disability. Among older adults, LVR should emphasize individuality in adaptation, engagement and learning in promoting their active participation and agency in modern digital society.

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