Participation of the visually impaired elderly
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Summary
In the Netherlands, 79% of the visually impaired persons are aged 65 years and over. Due to aging of the population the number of visually impaired persons will increase. Vision loss has a profound impact on daily functioning and poses a severe threat to the independence of visually impaired persons. Previous studies among the visually impaired elderly mostly focused on clinical and functional outcome measures. Limited knowledge exists on social outcomes of vision loss such as participation in daily life. The concept of participation was introduced by the World Health Organization (WHO; 2001) in the International Classification of Functioning, Disability, and Health (ICF), and is defined as “involvement in life situations”. Knowledge about participation is important, not only from the individual perspective but from the societal perspective as well: it gives an impression to what extent people are integrated in society. The main purpose of the study described in this thesis is: (1) to get insight in the degree of participation of visually impaired elderly persons and to identify determinants of this participation; and (2) to develop and test a multidisciplinary group rehabilitation program which aims to enhance the level of participation of the visually impaired elderly. These aims resulted in the following research questions that will be addressed in this thesis:

1. To what extent do visually impaired elderly persons participate in society?
2. Which biological, social and psychological factors determine participation of visually impaired elderly persons?
3. What is the prevalence of loneliness among visually impaired elderly persons and what are the determinants of loneliness among visually impaired elderly persons?
4. What is the effect of a multidisciplinary group rehabilitation program on participation (i.e., the primary outcome) and on physical and psychosocial functioning (i.e., the secondary outcomes)?

In order to answer the research question, two studies were performed: a cross-sectional study and a pilot intervention study. In chapter 2, the methodologies of both studies are described. The cross-sectional study included 173 visually impaired elderly persons aged 55 years and over, who were referred to Royal Dutch Visio, region North Netherlands, in the year preceding the data collection. Data for this cross-sectional study were collected by means of telephone interviews. In addition to self-reported performance of participation, participation restrictions and loneliness were assessed as well as the determinants of participation and loneliness. To compare the degree of participation and loneliness of the visually impaired elderly with that of normally sighted peers, three reference data sources were used: (1) National Survey on Living Conditions (POLs) of Statistics Netherlands (CBS); (2) the Amenities and Services Utilization Survey (AVO) of the Social and Cultural Planning Office (SCP); and (3) the Longitudinal Aging Study Amsterdam (LASA).
Based on the results of the cross-sectional study, as well as three focus group interviews and an expert meeting, we developed the multidisciplinary group rehabilitation program *Visually Impaired elderly Persons Participating (VIPP)*. This program aimed to enhance participation in society of the visually impaired elderly. The 20-week program consisted of four components: (1) training of practical skills; (2) education, social interaction, and counseling and training of problem-solving skills; (3) individual and group-goal setting; and (4) a home-based physical exercise program. The effect of the VIPP-program was tested in a pilot study with a single group pre-test post-test design. This intervention study included 29 visually impaired elderly persons who formerly participated in the cross-sectional study. Data with respect to the primary outcome of the study (i.e., participation) and the secondary outcome (i.e., psychosocial functioning) were collected by face-to-face interviews. Field-based assessments of physical fitness were used to assess the secondary outcome of physical functioning. Data were collected at baseline (pre-test), half-way through the intervention, immediately after the intervention (post-test) and six months later (long-term follow-up).

Chapter 3 addresses the first research questions with respect to participation in society of the visually impaired elderly. In this thesis, we designated four chapters of the ICF-component ‘Activities and Participation’, that represent participation: (1) domestic life, (2) interpersonal interactions and relationships, (3) major life areas, and (4) community, social and civic life. The results showed that the majority of the visually impaired elderly was engaged in household activities, in shopping, in socializing with family, friend and neighbors, in hobby activities, and in activities of clubs or associations. Only a minority was engaged in going out to recreational, cultural and public places. Comparison with population-based reference data showed that the visually impaired elderly participated less in household activities and went less often to recreational places. No differences were found for the ‘interpersonal interactions and relationships’ domain of participation. With respect to participation restrictions, we found that 94% of the visually impaired elderly experienced restrictions in one or more domains of participation. The results of the cross-sectional study indicate that the visually impaired elderly do participate in society, but that in some specific domains they participate less than their peers and that participation restrictions are prevalent. These restrictions may affect the visually impaired elderly, since participation has a positive influence on physical and mental health, and on quality of life.

The study described in Chapter 4 aimed to identify factors that influence the level of participation of the visually impaired elderly. Insight in these factors is necessary for the development of the multidisciplinary group rehabilitation program for the pilot intervention study. The impact of the various factors was investigated according to the biopsychosocial model. To examine the associations of the three components of this model with participation, a hierarchical model approach was applied. Of the biological factors,
vision-related variables (i.e., severity, duration and primary cause of the visual impairment) had no effect on participation. In contrast, perceived physical fitness was associated with participation in domestic life. With respect to the social status variables (i.e., partner status, social network size and social support), social network size was associated with participation in major life areas (i.e., voluntary work). The multivariate hierarchical regression analyses showed that the psychological component (i.e., mental health, helplessness, and the self-management abilities self-efficacy and taking initiatives) contributed to the explained variance of participation across the domains. A significant association was only found for helplessness and participation in domestic life. Perceived importance of participation appeared to be a major determinant of participation. Importance refers to the value that an individual attaches to a specific domain of participation. The results of the study presented in this chapter indicate that the rehabilitation program that will be developed and aims to enhance the level of participation should have a multidisciplinary approach, including physical, psychological and social work intervention techniques.

Chapter 5 focuses on loneliness among the visually impaired elderly. Loneliness is an unpleasant experience, encompassing a lack of (quality of) certain relationships. The purpose of the study described in this chapter was twofold: (1) to identify the degree to which visually impaired elderly experience feelings of loneliness as compared to their normally sighted peers; and (2) to examine the self-management abilities self-efficacy and taking initiatives as determinants of loneliness. Self-management abilities are internal resources which refer to behavioral and cognitive abilities that people use to manage their external resources such as friends and social support. The results of the cross-sectional study showed that loneliness was present in 50% of the visually impaired study population. In comparison, 29% of the normally sighted reference population experienced loneliness, which is a significant lower percentage. In addition, the average loneliness score in the study group was higher than in the reference population indicating that the visually impaired elderly perceive more loneliness. A multivariate hierarchical regression analysis showed that the self-management ability self-efficacy was the strongest determinant of loneliness. In addition, partner status and self-esteem were associated with loneliness. Vision-related variables (i.e., severity and duration of the visual impairment) were not associated with loneliness. In conclusion, this study indicate that the visually impaired elderly are a high-risk group for loneliness. Furthermore, our results suggest that self-management training provides the visually impaired elderly with skills and resources to manage the practical, social and emotional consequences of vision loss and may therefore be effective in reducing feelings of loneliness among the visually impaired elderly.
Chapter 6, 7 and 8 present the results of the pilot intervention study on the effectiveness of the multidisciplinary group rehabilitation program VIPP. Chapter 6 focuses on the effectiveness of VIPP on four aspects of participation: (1) frequency; (2) restrictions; (3) satisfaction; and (4) autonomy. In this study, the Utrecht Scale for Evaluation of Rehabilitation - Participation (USER-P-version 8) and the Impact on Participation and Autonomy questionnaire (IPA) were used to assess these four aspects of participation. Although at scale level there were no statistically significant changes, the effect sizes indicated a small decrease in restrictions in participation and a small increase in satisfaction with participation, as well as a medium improvement for autonomy outdoors. At item level, improvements tended to occur in frequency of housekeeping, in restrictions in housekeeping and outdoor activities, and in satisfaction with the partner relationship. In addition, satisfaction with leisure indoors and autonomy regarding using leisure time tended to increase. The tentative conclusion of the pilot study is that the VIPP-program modestly benefits perceived restrictions in participation, satisfaction with participation and autonomy outdoors of the visually impaired elderly.

The study presented in Chapter 7 aimed to examine the effects of the VIPP-program on two indicators of physical functioning, namely aerobic endurance and functional mobility. The 2-minute step test and the Timed Up and Go test (TUG) were used as performance-based measures of aerobic endurance and functional mobility, respectively. The results showed that both aerobic endurance and functional mobility improved not only immediately after the intervention but at long-term follow-up as well. The effect sizes were moderate to large.

In Chapter 8, the effectiveness of the pilot study on five indicators of psychosocial functioning (i.e., adaptation to vision loss, helplessness, self-efficacy, mental health and fear of falling) is described. We found statistically significant changes for three out of the five psychosocial outcome measures. There was an improvement in adaptation to vision loss and self-efficacy, and the feelings of helplessness decreased (medium to large effect sizes). The results suggested that the VIPP-program has both short- and long-term benefits. Immediately after completion of the intervention, we found an increase in adaptation to vision loss and self-efficacy as well as a better mental health. In addition, helplessness and generic and vision-specific fear of falling decreased. The 6-months follow-up measure indicated an increase in adaptation to vision loss, less feelings of helplessness, a better mental health and less vision-specific fear of falling. In contrast, we found a decrease in self-efficacy and an increase in generic fear of falling.

The pilot intervention study is a first step toward documenting the effectiveness of the newly developed multidisciplinary group rehabilitation program VIPP. Although the findings are based on a small-scale study, the results justify the conclusion that the program has the potential to improve the various factors of participation not only directly, but also indirectly by changing the influencing factors of participation (i.e., physical and psychosocial functioning).
In the final chapter, the results of this thesis are summarized and discussed, and implications for practice and research are addressed. The results of the cross-sectional study underscore the prevalence of restrictions in participation among the visually impaired elderly. Despite these restrictions, the visually impaired elderly do participate in society. However, they participate less in society compared to peers. Perceived importance appears to be a major determinant of participation. Physical health, along with social and psychological status, also affect participation. The results showed, in addition, that the visually impaired elderly are at risk for loneliness. The self-management ability self-efficacy is the strongest determinant of loneliness. Future studies have to show if factors that were not assessed in this thesis, such as environmental factors, contribute to the explained variance of participation and loneliness.

The pilot intervention study on the effectiveness of the VIPP-program showed that the program modestly benefits the subjective aspects of participation (i.e., restrictions, satisfaction, and autonomy). With respect to the secondary outcome measures, this thesis showed that participation in the VIPP-program improves physical and psychosocial functioning. These results are a good basis for the further development and implementation of the VIPP-program. Based on the information that was collected during the evaluation sessions with the participants and with the supervisors, recommendations are made regarding the target population, the group composition, the content, duration and frequency of the VIPP-program, as well as regarding the individual goals, and the feasibility of the home-based exercise component of the program. The effectiveness of the VIPP-program needs to be endorsed in future further studies, preferably in a randomized controlled design. Moreover future research may provide insight in what makes the VIPP-program work.