**Health and participation problems in older adults with long-term disability**

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**ABSTRACT**

**Background**. More attention and understanding of the health and participation problems of adults with early and later onset disabilities in the Netherlands is needed.

**Objective.** To explore health/participation problems and unmet needs in adults aged ≥40 years with long-term disabilities and their relationship with the time of onset.

**Methods.** Participants were recruited in the Netherlands through newsletters and social media to participate in a web-based questionnaire. The questionnaire assessed background characteristics, (change in) health/participation problems, and unmet needs. Spearman's rho was used to examine the relationships with time of onset.

**Results.** Of the 163 survey respondents, 42% acquired their disability before age 25 years and reported fatigue (77%), walking problems (66%), and pain (59%). In 21% of the respondents with early-onset disability fatigue, pain and depressive feelings co-occurred. Early-onset disability correlated with joint deformities, pain and anxiety. Participation problems included loss of income and fewer social activities. Early-onset correlated with the need for more information about diagnosis and prognosis.

**Conclusions.** People aged over 40 years with long-term disability have significant and increasing health and participation problems. Adults with early-onset disability are more likely to have health or participation problems than adults with late-onset disability. Early identification is needed for preventive care and access to specialized services that focus on improving and maintaining physical symptoms, energy management, and participation.

**Introduction**

Individuals with early acquired (before age 25 years) chronic illnesses or physical disabilities (i.e. early-onset disabilities) are becoming older and living longer with their disability. The majority now reaches age 40 years or over and participates in society.1 Although some American studies have addressed the employment issues of people with long-term disabilities,2,3 too little attention is given by healthcare providers, municipal consultants, researchers and policymakers to this expanding group, despite that they require specific care and support. Young adults with cerebral palsy (CP) or spina bifida have significant health complaints that justify periodic follow-up.4-6 Aging with early-onset disabilities is often accompanied by pain, fatigue, depressive symptoms, loneliness and the early manifestation of several health problems.1,7-9

Also, individuals with late-onset disabilities (i.e. after age 25 years) face health problems at a relatively young age.1 People with multiple sclerosis (MS) report fatigue, speech and swallowing problems and incontinence, and those with spinal cord injury (SCI) more frequently have osteoporosis, depression and diabetes.1,7-9 Consequently, many middle-aged or older people with long-term disabilities not only have health complaints, but also face participation problems.10

Individuals with early-onset disability are at greater risk for health problems than those with late-onset disability.1,11 Although persons with early-onset disability have often received intensive pediatric care, knowledge and interventions in adult healthcare services are often suboptimal. In contrast, people with late-onset disability regularly attend adult healthcare services. Therefore, it is important to investigate which problems people with early-onset disability have compared to individuals with late-onset disability. In addition, living with early-onset disability and, consequently, more physical strain, may result in earlier onset of health problems.1,11 In this group, such problems tend to go unrecognized or neglected by the adults themselves, and by primary care and support services;12 this is partly due to lack of knowledge and/or no experience on how to tailor both healthcare and support services to their individual needs.

The present study investigates the health/participation problems and unmet needs of people aged ≥40 years with a long-term disability and examines whether individuals with early-onset disabilities are at risk for higher self-reported occurrence of health/participation problems.

**Methods**

Data collection

The BOSK (Dutch Association of Physically Disabled Persons) conducted an online study to obtain insight into the health/participation problems in middle-aged/older adults in the Netherlands with a long-term disability. Inclusion criteria were aged ≥40 years, and living with the disability for at least 10 years. Persons aged ≥40 years were recruited based on clinical experience showing that, from this age onwards, more health and community participation problems become manifest. Timely intervention is essential, since people of this age are still socially active. Respondents were invited via newsletters/websites of various Dutch Patients’ Organizations and via social media to participate in the online survey that took place between September and December 2013.

An online method was chosen because about 96% of persons in the Netherlands aged 45-65 years have access to the internet.13 Other advantages of an online questionnaire are that it easily targets a large number of people and that it can be completed at their convenience. However, participants also had access to a printed questionnaire to be completed by hand and returned via the regular postal service. The questionnaire was tested prior to data collection. The method used in this study was similar to that in an earlier Dutch survey.4

The convenience sample consisted of 163 respondents (only one respondent returned the questionnaire by regular post).

Measurements

A distinction was made between early-onset disability (at age <25 years) and late-onset disability (≥25 years). Personal characteristics (sex, age, education, living status), diagnosis, health problems, and community participation of respondents with long-term disabilities were self-reported and assessed.

Education comprised three levels: 1) low [primary and low secondary education (middle/junior high school)], 2) medium (higher secondary education and lower vocational education), and 3) high (higher vocational education and university). Based on literature and clinical experience, 28 health problems were evaluated and categorized according the International Classification of Functioning, Disability and Health.14 Respondents were asked to indicate on a 5-point Likert scale whether they experienced health problems (1=never to 5=always) and whether these complaints had changed since they had reached 40 years of age (1=Much better now to 5=Much worse now). Both the complaints and level of deterioration were dichotomized (positions 1-3 vs. positions 4-5): occurrence (0=Never to sometimes, 1=Often to always) and deterioration [0=Much better now to Unchanged, 1=(considerably) Worse now]. The age of 40 years was used as cut-off because clinical experience shows that health/participation problems become manifest at a relatively young age.

Items on the perceived quality of life were derived from the SF-12.15 Three items were included: 1) general perceived health (1=excellent to 5=poor), 2) activity limitations due to pain (both indoors and outdoors) (1=not at all to 5=very much); and 3) experiencing depression or sadness (1= continuously to 6=never).

The questionnaire asked for current perceived level of being impaired at age 40 years (1=mild, 2=moderate, 3=severe); this concerned the subjective perception of one’s level of impairment based on three response categories. The degree of independence in activities of daily living (ADL) was measured with the Barthel Index (range 0-20, Cronbach's alpha 0.87)16 with higher scores indicating a higher degree of functional level. Questions were also asked about: decline in participation in the areas of mobility, leisure, social relationships, income and work (1=no, 2=yes)

Unmet needs were identified by the Southampton Needs Assessment Questionnaire.17 The domain scores (information, mobility, social activities, family role, volunteer organizations, finance, housing, formal health services and formal social services) were transformed to sum scores (0-100), with higher scores indicating greater unmet needs.

**Analyses**

Descriptive statistics were reported. Differences between the early-onset disability and late-onset disability subgroups were tested with t-tests and Chi2-tests. Correlations between onset of disability and health/participation problems and unmet needs were examined with Spearman's rho. In case of missing data, these respondents were excluded from analysis.

The SPSS 20 was used for statistical analyses.

**Results**

*Sample*

A total of 62 men (38%) and 101 women (62%) participated (n=163); mean age was 58.8 (SD 8.2, range 42-86) years, 42% had an early-onset disability, and 58% had a late-onset disability with onset at an average age of 40 (SD 9.3) years (mean duration 20, SD 8.2 years). In the group with early-onset disability, CP (23%) was the most frequent diagnosis whereas this was MS (68%) in the late-onset group. Table 1 presents the background characteristics of the respondents.

*Health*

Respondents with early-onset disability most often reported fatigue (77%), loss of energy (71%), difficulty with walking (66%), and pain (59%) (Table 2). On average they had 7.0 (SD 4.5) health problems; 35% had both fatigue and pain, and 21% had fatigue, pain and depressive feelings.

Problems most frequently reported by persons with late-onset disability were: restrictions in walking (83%), energy loss (82%) and fatigue (78%) (Table 2). On average, this group reported 6.5 (SD 3.5) health complaints; 31% reported both fatigue and pain. Having an early-onset disability correlated with the health problems joint deformities (r=0.21, p=0.014), pain (r=0.20, p=0.021) and anxiety (r=0.24, p=0.004), whereas late-onset disability was associated with walking problems (r= -0.20, p=0.015).

Early-onset disability was associated with worsened fatigue (r=0.21, p=0.013), pain (r=0.19, p=0.031) and heartburn (r=0.22, p=0.013) (Table 3). Also, in the respondents with early-onset disability, 18% found themselves slightly impaired, 66% moderately impaired and 18% severely impaired; in addition, 5% rated the current level of impairment as less severe than at age 40 years, 32% rated it as the same, and 63% indicated that the severity of the level of impairment had increased (Table 1).

*Participation problems and unmet needs*

Respondents with early-onset disabilities experienced problems concerning income (75% of the 34 not employed), engaging in less activities (71%) and deteriorated mobility (69%) (Appendix I). They also reported that their social relationships deteriorated (45%) and experienced a decline in self-care skills (31%)

Respondents with late-onset disability reported problems with income (83% of the 51 not employed), deteriorated mobility (77%) and undertaking fewer activities (73%). Fewer social relationships (54%) and declined self-care skills (37%) were also reported.

Overall, relatively few unmet needs were reported (range 9.5-36.6). Unmet needs were similar for the respondents on 8 of the 9 domains, irrespective of the time of onset of the disability. For the domain ‘information’, especially respondents with early-onset disability needed information on the course/impact of their disability (mean 36.6, SD 29.5) compared to respondents with late-onset disability (mean 23.0, SD 24.8) (r=0.23, p=0.011).

**Discussion**

This survey shows that the occurrence of fatigue, pain and mobility problems are high among a heterogeneous sample of middle-aged/older adults with long-term early-onset disabilities. In addition, the large percentage of self-reported problems in community participation indicates that this group is confronted with both health problems and challenges in their societal functioning. Around 80% of those with late-onset disability reported fatigue and difficulty with walking, whereas having an early-onset disability was related to higher self-reports of joint deformities and pain and this group more often reported that fatigue, pain and heartburn had worsened.

One in four respondents with early-onset disability reported depressive symptoms, partly coinciding with pain and fatigue. In adults with CP and SCI the clustering of fatigue, pain and depression was also evident.6,18 Fatigue is also a determinant of depressive symptoms and perceived health in rheumatoid arthritis.19 Moreover, deteriorating health is often a forerunner of participation problems.20,21 This self-reinforcing process was confirmed in a subsequent qualitative study in which loneliness in aging adults with congenital disabilities is perceived as a major problem.22 Loneliness may be an underlying factor in the development of fatigue, pain and depression.23 In people with SCI, pleasurable activities and a sense of contributing to society result in better health later in life.24

Adults with early-onset disability reported a need for information about their condition and also require support in mobility and social activities. They also expressed a need for more formal health services (e.g. physicians, therapists); these needs permeated all ages and all domains in life. It is questionable whether people with a long-term disability have access to appropriate healthcare and support services, as their needs may be underestimated by healthcare providers.12 Adequate support is not always available.4,25 Given the many health problems and increased perceived severity of the disability, together with the decline in mobility/social activities, it may be extra burdensome to fulfill the role of a self-reliant citizen.26 Therefore, services should aim at supporting both the sense of agency (e.g. self-determination) and participation, as well as providing appropriate healthcare. Supporting these adults with life-long disabilities requires specific knowledge of the effects of these conditions at older age and the related treatment options. It is important that patients, primary care providers, district healthcare teams and municipal consultants are aware of the problems faced by these adults. This requires sensitivity from municipal consultants to acknowledge the (often) multiple problems that hamper the societal functioning of this group. Assessing support needs should not only address a person’s self-management capacities, but the hampering effects of the additional health/participation problems should also be included in the assessment of healthcare and support needs. A regular medical check-up might be advisable.

Rehabilitation plays a pivotal role in the treatment of this aging group; this requires development of knowledge/programs to support aging with long-term disabilities, including knowledge on the impact of the disability on the aging process, long-term management of the disability, and the (secondary) prevention of health/participation problems. Developing psychosocial support and interventions aimed at energy management for this phase of life, as well as promoting sustainable participation, are also important. Furthermore, prioritizing the complaints and phased treatment might be necessary to learn how to cope with a lifelong disability and generalize skills. One of the treatment objectives could also address the strengthening of one’s agency. A model to discuss agency over the entire span of life is disability management.27 By addressing the impact of one’s disability on fulfilling social roles and autonomy within the social context, one’s agency and support needs can be clarified.

The present study confirms that this group has some work-related problems.10,20,28 Working less hours or early retirement might be associated with feelings of not meeting societal expectations, or may be experienced as a liberation.20 Working part-time can contribute to a better balance between private life and work.28 An approach developed for young adults with physical disabilities to promote work participation,29 combined with the prevention of occupational disabilities, may also suit these older adults.

Overall, few relationships were found between the time of onset and health problems. However, except for difficulties with walking, both the occurrence and the extent of the worsening of some health complaints were in line with other reports that early-onset disability increases the risk for health problems.1 Our study adds to the evidence that persons with early-onset disability experience more pain and fatigue. A possible explanation is provided by the reserve capacity theory;11 this states that organ systems and bones gradually develop in the first two decades of life and create excess or reserve capacity and, from the third decade of life, the capacity starts slowly to decline. According to this theory, persons with early-onset disability build less capacity and, therefore, face aging-related problems earlier in their lifespan. In addition, living with disability and the subsequent strain accelerates the decline in capacity, resulting in earlier onset of health problems related to aging. More studies are required to unravel the underlying processes and the course of these complaints to better understand aging with life-long disability.

**Methodological limitations**

Our recruitment method may have promoted the participation of people who experience many problems and/or are active patients. However, we employed a broad recruitment method, and the use of social media and various recruitment channels is not unusual.4,30 Moreover, members of a patient organization tend to have long-term disabilities for a longer period compared to non-members, which strengthens our study objective.31 The over-representation of individuals with MS limited the representativeness and distorts the comparison between the two groups. Also, due to lack of data from the general population, no comparison can be made with aged-matched peers without a long-term disability. Nevertheless, the present results add to the evidence that aging with long-term disabilities increases the risk to health and the participation problems.1,6,9,10

Future studies should address the specific needs of this group compared to the general aging population. Although we did not assess the health problems using validated measures, these problems were based on literature and clinical experience to obtain the widest possible insight into health problems at this age. The prevalence found is largely in line with other studies.4,5 The other questionnaires on skills related to ADL and unmet needs were assessed using standardized measures.

**Conclusion**

These respondents aged 40 years and older with a long-term disability reported significant problems with health and community participation. The quality of healthcare services for the entire group requires attention, but specific attention is needed for aging people with early-onset disabilities regarding secondary prevention and the treatment of problems related to health and participation.

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