This is a summary of a research project of the BOSK – the Dutch association for people with physical disabilities conducted in 2013-2014. It surveyed health and participation problems among peopled with long-term conditions aged forty years and older. © BOSK, 2015

Abstract

Background

Persons with congenital or early-acquired disability or chronic illness (referred to as young acquired conditions) are getting older due to improved healthcare. The result is that they have to find their way in social roles and healthcare services for adults. Research and experiences of aging young people with acquired conditions show that they develop at a relatively young age health complaints and problems in participation. Yet still much is unknown. An online questionnaire survey was conducted in the Netherlands among people aged forty years or older with a chronic condition to assess the perceived healthcare needs and social functioning. Respondents were also asked to self-invented solutions. A distinction was made between two sub-groups, namely young people with early acquired conditions and those with late acquired (from 25 years) conditions.

Method

Respondents were recruited through websites, newsletters, and various patient organizations. The questionnaire consisted of a survey of health problems, healthcare needs, social functioning and participation, self-efficacy and quality of life. The structure of health problems was explored by factor analysis. By subgroup and the total sample, associations were explored using Spearman's rho. Qualitative information regarding problems and self-invented solutions in social functioning and participation was analysed thematically.

Results

The questionnaire was completed by 163 respondents (69 congenital and 94 late acquired). The subgroups were similar in terms of gender, severity of disability, functional level, self-efficacy, perceived health, and suffering from depressive complaints. Respondents with young acquired conditions were younger and experienced more limitations in everyday life due to pain. Subgroups nor total group differed from Dutch norm population regarding self-efficacy. Those older than 64 self-assessed their overall health the same as Dutch age-mates, although there was tendency for respondents with late acquired conditions to assess their health less often as (very) good compared to healthy age-mates (44% and 60.6% respectively)

Late acquired conditions was associated with walking problems (83%); respondents with young acquired conditions more frequently reported pain (59%), joint deformities (28%) and anxiety (19%), and reported more often energy loss (87%), fatigue (84%), pain (74%) and heartburn (27%) were worsened since the age of 40 years compared to respondents with late acquired conditions. Respondents with early acquired conditions relatively often suffered from the combination of fatigue and pain (35%) accompanied by depressive symptoms (21%). The factor analysis revealed nine clusters of symptoms.

Most health needs were seen in the domains of information about the conditions and support with social contacts and activities. Respondents with congenital or late acquired conditions did not differ in their healthcare needs in the majority of domains. However, respondents with young acquired conditions more often required information about (the consequences of) the condition. Healthcare needs were related to the number of health problems.

More than seven out of ten respondents reported that their mobility and activity levels deteriorated. Three in five of the employed respondents (29%) reduced their working hours; one in two workers has gone backward in income. Of the respondents without work, four out of five have less income. Respondents with young acquired conditions were more likely to work. They also reported more often that finding paid work was complicated by discouraging employers.

Reported problems included reduced mobility, motor function and increased dependence. The solutions focused on the use of tools and assistance, and acceptance and adaptation to the situation. Problems in activities were mainly caused by health problems and reduced mobility. Solutions were the use of assistive devices, acceptance and more planning and/or structuring the activities. Motor and health problems were often mentioned as a cause of problems in personal care. The use of resources and seeking more assistance sometimes solved the problems, others looked for alternatives to continue their care without extra help themselves. Loneliness due to fewer social contacts was often reported. The effects of the condition and fewer obligations outside were often causes of loneliness. Contact via alternative channels was a way to maintain social contacts. Doing volunteer work, peer contact and going out for a walk were strategies that were applied also.

Health problems often led to work-related problems. Less work led to financial problems. Adapting the work and stop working and starting with volunteer work were solutions. Loss of income was often cited as a problem. Some were faced with illness-related costs. Watching the sales and buy at thrift stores were ways to reduce costs. Sometimes people asked help from family or friends.

Conclusion

Both the frequency and the increase in symptoms such as fatigue, walking difficult, loss of energy and pain emphasize the experienced burden of these people. The problems in health, activities and participation, and healthcare needs are very intertwined. In recent literature, the clustering of pain, fatigue and depressive symptoms are often mentioned. Reported problems in reduced social functioning, often combined with a limited social range and solitude, put recent decentralizations of care that citizens expect more of themselves and their social network is in a different perspective. Given the problems outlined illustrates the need for professional support. From the rehabilitation and primary care a proactive approach is needed, to look multidisciplinary at the health, care needs and problems in social functioning.