

Experiences of being parents of young adults living with recessive limb-girdle muscular dystrophy from a salutogenic perspective

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Received 5 December 2016; received in revised form 23 January 2017; accepted 31 January 2017

Abstract

Recessive limb-girdle muscular dystrophies (LGMD2) involve progressive muscle weakness. Parental support is important for young adults living with LGMD2, but no study has been identified focusing on the parents' experiences. The salutogenic perspective concentrates on how daily life is comprehended, managed and found meaningful, i.e. the person's sense of coherence. The aim of this study was to describe, from a salutogenic perspective, experiences of being parents of young adults living with LGMD2. Nineteen participants were included. Data were collected by semi-structured interviews and the self-administrated 13-item sense of coherence questionnaire. Interview data were analysed with content analysis and related to self-rated sense of coherence. The result shows experiences of being influenced, not only by thoughts and emotions connected to the disease but also by caregiving duties and the young adults' well-being. Simultaneously, difficulty in fully grasping the disease was expressed and uncertainty about progression created worries about future management. Trying their best to support their young adults to experience well-being and to live fulfilled lives, the importance of having a social network, support from concerned professionals and eventually access to personal assistance was emphasized. The need to have meaningful pursuits of one's own was also described. The median sense of coherence score was 68 (range 53–86). Those who scored high (≥ 68) described satisfaction with social network, external support provided, work and leisure activities to a greater extent than those who scored low (< 68). The result shows that the young adults' disease has a major impact on the parents' lives. Assessment of how the parents comprehend, manage and find meaning in everyday life may highlight support needed to promote their health.

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Keywords: Limb-girdle muscular dystrophy; Parents; Sense of coherence

1. Introduction

The muscular dystrophies (MD) are a group of disorders that involve progressive muscle weakness and increased dependency on other people, which affects not only the person but the whole family [1]. Recessive limb-girdle muscular dystrophies (LGMD2) refer to a group of MDs that are genetically and clinically heterogeneous but have in common an involvement of the proximal musculature in the shoulder and pelvic girdles [2]. Recent findings show that informal social support from parents is important for young adults living with LGMD2 to manage daily life, and often parents worked as personal assistants [3], which is human aid to enable independence and participation in society for persons with functional impairments [4]. Therefore,

the parents' situation and need of support have to be recognized by healthcare professionals, but the literature review found no previous study focusing on the parents' experiences.

Today, over 20 different forms of LGMD2 have been identified [5]. The age of symptoms debut varies from early childhood to adulthood, and progression rate varies and may not be linear. Involvement of the cardiac and respiratory systems can develop in some of the forms of LGMD2. This means that some persons may be as severely affected as individuals living with Duchenne muscular dystrophy (DMD) whereas others have late onset and mild progression [6]. Previously, parents of young adults living with DMD have been found to have an important role in supporting their sons [7], but the transition to adulthood has been shown to be a challenging time for the young adults and their parents [8,9]. Also, parents of adult persons diagnosed with MD have been described as perceiving that they have more responsibilities than parents with healthy offspring [10] and they may experience a substantial caregiver burden, but

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they also value caregiving as important and rewarding [11]. Moreover, life satisfaction among female caregivers is associated with social support, resiliency, income and form of MD [12]. This study is, however, to our knowledge, the first study that focuses on experiences of being parents of young adults living with LGMD2 from a salutogenic perspective.

The salutogenic perspective was introduced by Antonovsky [13] and focuses on health-promoting factors and what causes a person's movement towards health rather than what is the aetiology of disease. Health and disease are viewed as a relative continuum and each person can at a given point of time be found somewhere along this health-disease continuum. Where on the continuum a person is located depends on the person's sense of coherence (SOC), which is based on the three components: comprehensibility, manageability and meaningfulness. Comprehensibility refers to whether the person perceives that inner and outer stimuli make sense in terms of being coherent, structured, predictable and clear. Manageability refers to the extent to which the person feels confident that internal and external resources to cope are available. Meaningfulness refers to areas in life that are valuable for the person and the perception of whether difficulties in life are worth an investment of engagement. The concept of SOC has been operationalized in the SOC questionnaire [13]. The salutogenic perspective was chosen as a base in this study to provide an overall view of the parents' situation and what support is needed to manage everyday life. Their young adults being affected by LGMD2 can be regarded as an ever-present stressor, and with no cure currently available the parents need to focus on internal and external resources available for coping in order to maintain or promote their health. Any characteristic of the person or the environment that can facilitate stress management is regarded as a generalized resistance resource. It involves all potential resources that the person is able to mobilize and use to manage difficulties. The generalized resistance resources provide the person with coherent and meaningful life experiences which in turn strengthen the person's SOC [13].

Considering the importance of parental support for young adults living with LGMD2 [3] it is important to gain understanding about the parents' experiences in order to optimize support provided to these families. The aim of this study was to describe, from a salutogenic perspective, experiences of being parents of young adults living with LGMD2.

2. Participants and methods

This study has a descriptive design, with data collected by semi-structured interviews and the self-administered 13-item sense of coherence questionnaire (SOC-13). Semi-structured interviews provide an opportunity for participants to describe personal experiences within a given frame [14], and the SOC-13 questionnaire [13] was used to describe the participants' SOC and to mirror the interview data. Thus, the combination of collected data enabled a more complete picture of the participants' experiences [14].

2.1. Participants

A purposeful sampling procedure was used [14]. Inclusion criteria were parents of young adults diagnosed with LGMD2. Young adults, aged 20–30 years, who participated in a previous study about experiences of living with LGMD2 [3] forwarded a letter containing information about this study to their parents. All of the young adults had at least one parent who agreed to participate ($n = 19$) and the principal investigator (first author) settled the time and place for the interviews.

2.2. Interviews

Semi-structured interviews were conducted between October 2012 and November 2013. An interview guide was formulated based on the main areas that describe a person's SOC, namely comprehensibility, management and meaningfulness [13]. An overview, showing how these main areas in the concept of SOC were defined in this study and interview questions asked to capture the participants' experiences, is presented in Table 1.

The interview guide was tested with the participants in the first three interviews (included in the study) and no changes were made.

The interviews were held individually or with parental couples in secluded rooms chosen by the participants, mainly at their homes. In families where two parents participated, they all chose to be interviewed together and both came to speak throughout these interviews. All the interviews were performed by a nurse (first author). The interviewer did not have any professional or personal relation to the participants but has knowledge about the care of persons diagnosed with MD as an anaesthetic/intensive care nurse and being a next of kin to a

Table 1
Overview of the main areas based on the concept of sense of coherence [13], their definitions and interview questions used in the study about experiences of being parents of young adults diagnosed with recessive limb-girdle muscular dystrophy (LGMD2) from a salutogenic perspective.

Main areas	Definitions	Interview questions
Comprehensibility	Cognitive component that refers to experiences of what it means being parents of young adults diagnosed with LGMD2.	Could you describe what it means being a parent of a young adult living with LGMD2?
Manageability	Behavioural component which includes experiences of whether or not internal and external resources to cope are available.	Is there any support that you would need that you do not have access to? If so, could you describe what it is? Is there any support that your son/daughter would need that he/she does not have access to? If so, could you describe what it is?
Meaningfulness	Motivational component that refers to areas in life which are important and bring joy for the person.	What do you experience as the most meaningful in life?

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