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## RESEARCH ARTICLE

# Ageing with Muscular Disease

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### Abstract:

#### **Background:**

The demographic development with an ageing population is predicted to be the next global public health challenge. Advances in medicine and the socioeconomic development have reduced mortality and morbidity due to infectious conditions and non-communicable diseases. The increase in longevity will not be restricted to healthy people.

#### **Objective:**

To understand how people with muscular diseases experience ageing.

#### **Method:**

A literature review was conducted using the Matrix Method developed by Garrard (2007). This systematic method was used to identify, describe and interpret studies, irrespective of the methods applied. To avoid the exclusion of important sources, experiences and topics, we chose an integrative approach that accommodates the inclusion of studies with different methodologies. People with MD have gradually extended their life expectancy during the last 30 years. Thus, we reviewed the literature regarding MD and ageing without time limit.

#### **Results:**

We identified three themes: 1) Slowing down early 2) Accepting lifelong deterioration and 3) Striving for normality.

#### **Conclusion:**

People with MD live in a field of tension between a feeling of autonomy and normality and difficulties coping with reduced physical abilities. Getting older accentuates this tension since the physical strength diminishes and it is harder to maintain autonomy. The bodily challenges may coincide with the end of the rehabilitation people living with MD have received. Seemingly, no age-related rehabilitation is offered, and people living with MD are thus at risk of an unnecessarily passive life.

**Keywords:** Ageing, Disability, Matrix method, Muscular disease, Review.

## BACKGROUND

The demographic development with an ageing population is predicted to be the next global public health challenge. Globally, people aged 65 years and older will outnumber children below the age of five years during the next five years [1]. Advances in medicine and the socioeconomic development have reduced mortality and morbidity due to infectious conditions and non-communicable diseases. Along with fast urbanisation, modernisation, globalisation and changes in risk factors and lifestyle more people will live longer with chronic conditions [2]. In Denmark, it is estimated that 25% of the population will be above 65 years in 2035 ([www.dst.dk](http://www.dst.dk)). However, the increase in longevity will not be restricted to healthy people. A significant number of people with physical impairments also live longer [3]. A child with a lifelong disability (*i.e.*, spina bifida, cerebral palsy, Down's syndrome) had a life expectancy of nine years in 1930; today their life expectancy is 60 years [3]. Diseases with a later onset such as spinal cord injury and multiple sclerosis also have

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improved survival rates; this has already led to a growing population of older people living with these diseases [4, 5]. Among healthy people, ageing is normally associated with declines in strength as a result of a combination of neuro-musculoskeletal, structural, physiological, hormonal and lifestyle changes [6, 7]. Sarcopenia is the term used to describe the progressive loss of skeletal muscle mass and associated weakness related to ageing, and has been shown to affect older adults independent of age, sex, obesity, ethnicity, socioeconomic status, chronic morbidity and health behaviour [8]. For people living with physical impairment the functional declines associated with ageing may coincide with limitations in activity and threaten the ability to participate in daily life. The potential losses caused by ageing may be just as significant or perhaps worse for a person living with physical impairment than for a person experiencing weakness for the first time in old age. Declines in functional ability may disrupt former patterns of adaptation of and participation in activities related to work, family, daily living and leisure [9, 10]. Moreover, for those with physical impairment the likelihood of comorbidity increases with age, adding to the complexity and costs related to health care needs [11]. People with muscular diseases (MD) have a lifelong unpredictable disease that may at some point be complicated by age-related changes.

MD is characterized by a progressive degeneration of muscle strength, which previously leads to wheelchair dependency, respiratory insufficiency and early death. However, people with MD have in recent years prolonged their life expectancy significantly [12]. MD was previously called 'diseases of the childhood', but due to the advances in medical management of comorbidities, individuals with MD survive well into adulthood [12].

One group of people who are facing decades of unforeseen adult life despite MD is people living with Duchenne muscular dystrophy (DMD) [13]. Especially one intervention has had a profound effect on the epidemiological profile of DMD. The introduction of assisted ventilation from the mid and late 1980s and onwards has resulted in a new patient population emerging in various countries [14, 15]. In a Danish population of people with DMD treated with home mechanical ventilation, Jeppesen *et al.* were one of the first to address life conditions and problems in adulthood and predict a need for rehabilitation in an ageing population of patients with DMD. In some countries, people with DMD live in their own homes assisted by personal helpers. As in other people with DM their dependence on care increases with age and they become totally dependent on care at an early age although they strive to live an active and independent life [16]. Ageing is now a living condition even for those born with a disease like DMD; within a few decades life expectancy has increased with 30 to 40 years [16]. Only few have so far reached old age and little is known about the life experiences of ageing with DMD. It is plausible that people with DMD and MD have special needs compared to the healthy ageing population. Thus, it is increasingly important to understand the needs and experiences of those ageing with MD and to take these into account in the planning for care and retirement. So far, knowledge of the experiences of people aging with MD is sparse. The aim of this study was to understand how people with MD experience ageing.

## METHOD

A literature review was conducted using the Matrix Method developed by Garrard (2007). This method captures a topic consisting of knowledge and research from different methodological areas, implying that the topic guides the systematic review process [17]. This systematic method was used to identify, describe and interpret studies, regardless of the methods used in the original studies. To avoid the exclusion of important sources, experiences and topics, we chose an integrative approach that accommodates the inclusion of studies with different methodologies [18]. Sandelowski and Barosso [18] have clearly articulated the challenges with attempting if a research report is truly representative of a grounded theory study, an ethnography, or another qualitative research method. Taking their lead, we focused on the topic in the included papers review and less on the methodological approach used in the primary papers. Since the life expectancy of people with MD has gradually increased during the last 30 years, we reviewed the literature regarding MD and ageing without defining a time limit.

## SEARCH STRATEGIES

The search strategy involved a computerized and a manual search. The computerized search was conducted together with an information scientist in the following databases: PubMed, Cinahl, Scopus, Embase and SveMed+. We used the search terms:

'Ageing', 'old', 'adult', 'lived experience', 'daily living', and 'neuromuscular disease'. The search was conducted using these MeSH words or major subject headings one by one and in combination.

The search resulted in 117 hits of which 89 were excluded based on title, abstract and duplicate status. Both authors

performed a detailed screening of the remaining 28 articles for relevancy. Seventeen full-text articles were assessed for eligibility. Finally, six articles were selected and further analysed (Fig. 1).

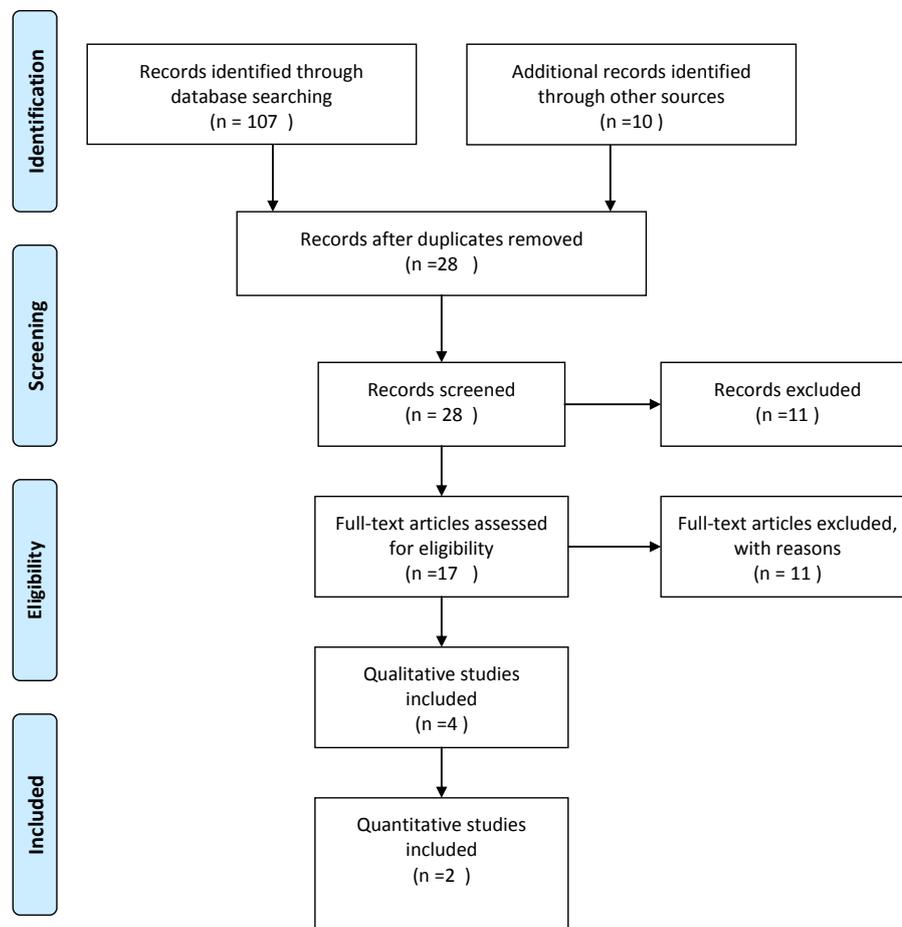


Fig. (1). PRISMA flow diagram.

## INCLUSION CRITERIA

This review included studies without focusing on the age of the study populations. We used a life course perspective as recommended by Jeppsson Grassmann *et al.* [19] exploring ageing in the life of people with functional impairment. This implies that the focus is on the meaning of impairment in the totality of life's dynamics, where ageing is seen as a lifelong process [19].

## RESULTS

We analyzed original, empirical studies on experiences of people living and ageing with MD to include the variety of experiences related to the topic. Below, we summarize the experiences of people with MD as they are described in the included studies. To provide an overview, studies are categorized into three themes: 1) Slowing down early 2) Accepting lifelong deterioration 3) Striving for normality acknowledging that the experiences are interconnected and often inseparable.

### SLOWING DOWN EARLY

Ageing with DM is living a life described as slowing down early [20]. The physical body deteriorates faster than those of peers; thus, being 37 years old may be experienced as being 65 years old [21]. This physical deterioration increases the physical limitation and may lead to isolation and loneliness. Deterioration may result in a feeling of being a minority in an able-bodied world. This feeling is often perceived as helplessness where other people are more interested in their impairment than their personality. People with MD wish that other people focus on their abilities instead [21].

Another issue in ageing with physical impairment is safety. When the body slowly deteriorates, life changes and living with ageing increases the need for support from family, friends and others. To ensure safety, people with MD need to plan and organise the increased use of mobility devices [10] and the increased need for assistance in personal care [22]. Even though early ageing is described as a 'fine quality of life', it is not the same as a trouble free life. People living and ageing with MD experience worries about the disease as they had earlier in life but also a concern related to loss of functionality, *e.g.* reduced ability to write, operate the wheelchair and to eat unaided [23]. Ageing also implies a prospective fear of breathing and heart problems and as a consequence a fear of early death. Overall, uncertainties related to the progression of disease and the consequences for daily life generate worries about the future [23]. Slowing down early means adapting needs to decreasing physical capacity and requires planning and daily organizing of the help needed [10, 21, 23].

### **ACCEPTING LIFELONG DETERIORATION**

People living with MD struggle to accept the continuous deterioration of the body [10, 21]. Getting used to this condition presupposes an acceptance of the whole life situation. The chronic disease and the deterioration are incorporated in daily life both being a challenge and a limitation [10, 23]. As people with MD get older changes caused by the disease could be hard to discern from age-related changes and they constantly monitor their body. Most people with MD have difficulties performing personal care tasks such as shaving, putting on make up and washing their hair and hands and these difficulties are more pronounced with age [10, 23] similar to the experience of pain and stiffness [10]. Over time the need for rest and sleep also increases [10, 24]. Thus, people with MD alter their activities [10]. In the middle of adulthood, typically in their 30s and 40s, people with MD may encounter age-related acute and/or chronic health-related problems causing temporary or permanent disruption in one or multiple areas of life [20]. At this stage of life they may lose the gains achieved in rehabilitation in young adulthood [20]. Such problems may generate the need to take action. Diet, exercise, and alternative therapy may be helpful in dealing with secondary impairments. In other cases coming to a level of acceptance can also initiate actions towards improving quality of life. Some alter their lifestyle, seek out different therapies or use mobility devices [21]. Overall, in their later life people with MD tend to accept their condition, despite reduced bodily functions [20 - 22]. Over time they get integrated knowledge of possible and limited activities as well as the ability to cope in a more relaxed way with the need for support [23, 24]. Time is described as a prerequisite for adaption to the limitations due to the usually insidious deterioration of MD [22]. However, some people with MD still worry about what the future will bring. They fear a passive old age with loss of functionality, decreased mobility, need of more assistive devices and dependence on others [23, 24].

### **STRIVING FOR NORMALITY**

Living with MD is a striving for normality through active living [21]. Some people with this chronic condition are heavily dependent on help from others, but this does not mean they are passive; the majority are actively directing their own lives. Performing tasks to handle and direct daily living provides a feeling of autonomy and normality [10], and people with MD mostly report a high quality of life [23]. On the other hand serious difficulties coping with reduced physical ability are also described as a part of daily living with MD [23]. In this field of tension people living with MD strive for normality, both as a personal experience and in the attitude of others. Managing daily life with work and family duties contribute to a perception of normality. Moreover, being authentic as a person with MD supports the self-image of normality [10]. The experience of autonomy can be achieved if no help in daily activities is needed, but also if assistance from other people is experienced as genuine support leading to autonomy [10, 24]. Similarly, technical aids and society resources may make it possible to be active leading to experiences of normality [10]. Throughout life people with physical impairments caused by MD learn how to manage their own bodies and move as effectively as necessary to control their environment and participate in activities that are meaningful to them [20]. The change from being independent to being in need of assistive devices and/or support from others is described as a psychologically demanding process where limitations caused by the disease have become a natural part of everyday life [24]. Ironically, as people with MD start losing their functional ability and find it more difficult to complete certain activities, they may no longer have access to services, be a part of programmes, and have the resources to address health problems and prevent disease progression [20, 20]. In some cases it is possible for people with MD to be financially supported by their municipality to hire their own personal assistants [21]. If the money granted is based on their own needs assessment it may be possible to take part in the activities that interest them, whereas needs assessment by social authorities may only include their basic health needs [21]. Managing domestic life may demand new solutions – for instance that partners or personal assistants completely or partly take over some tasks [24]. Having a close relationship to family and

being a parent contribute to the experience of 'living like most people' [24].

## DISCUSSION

The essence of our theme 'slowing down early' is that ageing is experienced as a quick process where the bodily deterioration forces people with MD to alter their lives and diminish demands to their abilities. This is in accordance with the normal ageing process, although this process is likely to happen over years among people without a chronic condition. However, for people living and ageing with MD their biological age is higher than their chronological age [25]. According to Vance *et al.* (2012) successful ageing is constituted by three components (1) avoiding disease and disability, (2) active engagement in life, and (3) maximizing physical and cognitive function. These three components are interrelated and support each other, but optimal cognitive function is essential in maintaining the other two components [26]. MD does not affect the cognitive function so people living with this disease have a good basis for successful ageing. However both 'disability' and 'disease' will always play a role in their lives, and may hinder the possibility of 'maximizing physical function'. Hence, for people living with MD successful ageing is primarily dependent on their capacity for dealing with the third component 'active engagement in living' and this may demand sensitive assistance from other people [27].

The identified theme 'accepting lifelong deterioration' showed that people living with MD tend to accept their disease relatively late in life. The theory of transition by Meleis *et al.* [28] 2000 may explain why people living and ageing with MD may be in two types of transition at the same time: A developmental transition due to ageing and a transition related to health and illness, where MD continues to progress simultaneously with the process of ageing. Among others the experience of transition includes one aspect that Meleis *et al.* [28] call 'critical points'. These points are usually associated with an increasing awareness of changes or more active engagement in dealing with the experience of transition. According to the theory of transition [28] a period of uncertainty is marked by fluctuation and continuous change, whereas final critical points are characterized by a sense of stabilization regarding new routines, skills, lifestyle, and self-care activities. This study showed that people living with MD and reaching an age that was previously considered unrealistic, live in a stage of continuous change. The disease may transform their life condition from day to day and they do not know whether the changes are irreversible or not. Getting older accentuates this uncertainty because ageing may add diverse physical and psychological challenges to the symptoms of the disease. Thus, the double transition means that people with MD live in constant uncertainty and threat of far-reaching changes without a stable life situation where acceptance of their condition can be formed. However, our findings show that people living with MD continuously struggle to find ways to deal with their bodily changes to stabilize their life situation, but new routines may suddenly be overturned by unpredictable changes caused by both disease and ageing.

According to the findings in the included studies of this review people living with MD are continuously striving for normality and even late in life some participants struggle with low self-esteem, though they have incurred their disease at birth and are said to 'age with disability' [29]. Goffman [30] describes abominations of the body as one type of stigma. People living with various deformities possess a stigma, an undesired differentness from what the people Goffman refers to as 'normals'. Stigmatized people are not considered as quite human and are treated in ways that reduce their life chances. Often though unintendedly an ideology is constructed to explain the inferiority of the stigmatized persons and to account for the dangers they represent [30]. Therefore, stigmatized people are aware of their inferiority; that means they are unable to keep the sense of inferiority out of their mind and this may generate a chronic feeling of anxiety [30]. This is in accordance with the findings in our study where the people living with MD seem to be constantly conscious of their physical impairment affecting their interactions with other people. According to Goffmann [30] the fear that others can disrespect a stigmatized person for something impossible to fix may, make encounters with 'normals' complicated. People with MD strive to be considered 'a whole person' and not just a diagnosis, though they have never belonged to the so-called 'normal' population. The gradual deterioration of the body and signs of ageing may increase their experience of belonging to a stigmatized group. Especially when considering that people living with MD may lose their previous access to rehabilitation due to age-related limitations. This may be experienced as a regulation formulated by 'normal' people but negatively affecting life chances of people with MD.

As people living with MD get older, bodily changes caused by MD may be hard to discern from age-related changes *e.g.* sarcopenia which is experienced by all people. However, no results included in this study deal with the complexity of MD and ageing and thus the possibility of confusing the signs of the disease with ageing. Both living with MD and ageing *per se* lead to an insidious course of weakness [7], but may require different kinds of support. Some communities have started to merge disability and ageing services, recognizing that individuals often need both [29]. In the studies

included in this paper the participants refer to 'services' or 'support' without specifying what kind of assistance they need. Some regret that they no longer have access to the rehabilitation they used to get, but they are seemingly not aware that receiving age-related rehabilitation may be an opportunity depending on available services in their local community. Access to other privileges could be an opportunity if people with MD were made aware of them. In general, the findings in this study showed that the knowledge of the specific needs among people living and ageing with MD is sparse.

There is a need for further research that examines what 'successful ageing' means for people living with MD and people living under comparable conditions. Also it could be interesting to investigate if it is possible to create a seamless transition from a life with determined rehabilitation to a life with age-related rehabilitation.

It should be acknowledged that the research represented in this review was conducted in Western countries why the findings may have a limited value in other parts of the world. Also data were collected in the participants private homes and the specific attributes of these surroundings has not been explored in this paper. Participants therefore need to make their own decisions to address the adverse effect to changes in life (48).

## CONCLUSION

People living with MD live in a tension between an experience of autonomy and normality and difficulties coping with reduced physical abilities. Getting older accentuates this tension since their physical strength diminishes and it is harder to maintain autonomy. Technical devices and sensitive assistance from other people may ease the life of people with MD, but still the unpredictability of disease and ageing makes it difficult to maintain a stable life situation. Moreover, it may be hard to sustain the desired level of activity though people living with MD draw on devices and help from other people. Some end up by diminishing their needs. Unfortunately the bodily challenges may coincide with the end of the rehabilitation services people living with MD have previously received. Seemingly, they are not automatically offered age-related rehabilitation, thus people with MD risk to live an unnecessarily passive life. Finally, a life with MD is a never-ending concern about how the surroundings see you. The physical deficits may generate an experience of being stigmatized, and this may be accentuated when rules and regulations do not seem to meet the needs people living with MD get when they age.

We suggest establishment of a seamless rehabilitation with no distinction between being young and old. Lifelong rehabilitation should be offered automatically without any effort from the people who need it regardless of their age.

## CONFLICT OF INTEREST

The authors confirm that this article content has no conflict of interest.

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