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It's time to talk about mobility disability and overweight

Quality of life and need of preventive measures from the perspective of people with mobility disability and public health nurses

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It's time to talk about mobility disability and overweight

Quality of life and need of preventive measures from the perspective of people with mobility disability and public health nurses

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Quality of life and need of preventive measures from
the perspective of people with mobility disability and
public health nurses

Marianne Holmgren



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DOCTORAL DISSERTATION

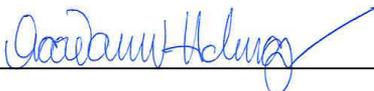
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Title and subtitle: It's time to talk about mobility disability and overweight. Quality of life and need of preventive measures from the perspective of people with mobility disability and public health nurses		
<p>Abstract</p> <p>Overweight and obesity are more common among adult people with mobility disability (MD). Epidemiological studies are sparse in Sweden when it comes to the prevalence of MD and weight, differences between people with MD compared to those without MD, as well as the association to HRQoL. In addition, general guidelines in obesity prevention and treatment adapted to people with MD are lacking in Sweden. This thesis comprises two quantitative (I, II) and two qualitative (III, IV) studies.</p> <p>The aim of Study I and Study II was to investigate the prevalence of mobility disability, overweight or obesity and the association to HRQoL and participation in society in two different populations in Sweden. The aim of Study III was to explore the experience of healthy weight among people with mobility disability and the aim of Study IV was to develop a theory which could explain how public health nurses adapt guidelines to decrease overweight and obesity in people with mobility disability.</p> <p>The results from Study I and Study II showed that people with mobility disability had higher prevalence of overweight and obesity in comparison to people without mobility disability. Despite this, Study II showed that the BMI did not increase more in people with mobility disability in comparison to those without mobility disability. The overweight or obesity has no higher association to low HRQoL or participation in society among people with mobility disability in terms of "a double burden". In addition, Study II showed that people with mobility disability had lower HRQoL and participated in society to a lesser extent than people without mobility disability. The results from Study III revealed that people with mobility disability experienced problems with maintaining or regaining a healthy weight. They experienced a vicious circle where overweight/obesity exacerbated both the mobility disability and the pain. This led to difficulties in being physical active, which in turn resulted in difficulties in maintaining or regaining a healthy weight. They said also that it was difficult to receive good advice from the health care professionals because of lack of competence. The results from Study IV revealed that the public health nurses hesitate to initiate a conversation about overweight or obesity independently of whether the people in front of them have mobility disability or not. They experienced that initiating a conversation with people with overweight or obesity was a sensitive issue but could be facilitated if they worked in teams at the health centres and had more time and resources.</p> <p>Despite the fact that people with mobility disability are overweight and obese to a greater extent than people without and have lower HRQoL and participate in society to a lesser extent, they are not a prioritized group with regard to health prevention. People with mobility disability experienced that health professionals at health centres do not raise the question of health prevention; or if they do, they do not understand their patient's situation. Public health nurses confirm that they do not raise the subject of overweight and obesity independently of whether the patient has mobility disability or not, because of its being so sensitive topic. Both people with mobility disability and public health nurses revealed that overweight and obesity prevention is not highly prioritized, and teamwork is suggested as a means to foster better lifestyle to decrease overweight and obesity.</p>		
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*You can't go back and change the beginning, but
you can start where you are and change the ending.*

C.S Lewis

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Abstract

Overweight and obesity are more common among adult people with mobility disability (MD). Epidemiological studies are sparse in Sweden when it comes to the prevalence of MD and weight, differences between people with MD compared to those without MD, as well as the association to HRQoL. In addition, general guidelines in obesity prevention and treatment adapted to people with MD are lacking in Sweden. This thesis comprises two quantitative (I, II) and two qualitative (III, IV) studies.

The aim of Study I and Study II was to investigate the prevalence of mobility disability, overweight or obesity and the association to HRQoL and participation in society in two different populations in Sweden. The aim of Study III was to explore the experience of healthy weight among people with mobility disability and the aim of Study IV was to develop a theory which could explain how public health nurses adapt guidelines to decrease overweight and obesity in people with mobility disability.

The results from Study I and Study II showed that people with mobility disability had higher prevalence of overweight and obesity in comparison to people without mobility disability. Despite this, Study II showed that the BMI did not increase more in people with mobility disability in comparison to those without mobility disability. The overweight or obesity has no higher association to low HRQoL or participation in society among people with mobility disability in terms of “a double burden”. In addition, Study II showed that people with mobility disability had lower HRQoL and participated in society to a lesser extent than people without mobility disability. The results from Study III revealed that people with mobility disability experienced problems with maintaining or regaining a healthy weight. They experienced a vicious circle where overweight/obesity exacerbated both the mobility disability and the pain. This led to difficulties in being physical active, which in turn resulted in difficulties in maintaining or regaining a healthy weight. They said also that it was difficult to receive good advice from the health care professionals because of lack of competence. The results from Study IV revealed that the public health nurses hesitate to initiate a conversation about overweight or obesity independently of whether the people in front of them have mobility disability or not. They experienced that initiating a conversation with people with overweight or obesity was a sensitive issue but could be facilitated if they worked in teams at the health centres and had more time and resources.

Despite the fact that people with mobility disability are overweight and obese to a greater extent than people without and have lower HRQoL and participate in

society to a lesser extent, they are not a prioritized group with regard to health prevention. People with mobility disability experienced that health professionals at health centres do not raise the question of health prevention; or if they do, they do not understand their patient's situation. Public health nurses confirm that they do not raise the subject of overweight and obesity independently of whether the patient has mobility disability or not, because of its being so sensitive topic. Both people with mobility disability and public health nurses revealed that overweight and obesity prevention is not highly prioritized, and teamwork is suggested as a means to foster better lifestyle to decrease overweight and obesity

Abbreviations

BMI	Body mass index
CDC	US Centers for Disease Control and Prevention
CIs	Confidence intervals
EQ-5D	EuroQol – 5 dimension instrument
GHQ-12	The General Health Questionnaire
GRAIDs	Guidelines, Recommendations, Adaptations Including Disability
GT	Grounded theory
HC	Health centre
HRQoL	Health-related quality of life
ICF	International Classification of Functioning, Disability and Health
MD	Mobility disability
OR	Odds ratio
PA	Physical activity
PHN	Public health nurse
PHS	Public health survey
QoL	Quality of life
SCB	Statistic Sweden
SF-36	Short Form Health Survey
WHO	World Health Organization

Original papers

This thesis for the doctoral degree is based on the following papers, referred to in text by their Roman numerals:

- Paper I Holmgren, M., de Munter, J., Rasmussen, F., Sandberg, M., Ahlström, G. Health-related quality of life and participation in the society among people with and without mobility disability and its associations to obesity: a cross-sectional population study in southern Sweden. *Healthcare* 2017, 5(4):79.
- Paper II Holmgren, M., Lindgren, A., de Munter, J., Rasmussen, F., Ahlström, G. Impacts of mobility disability and high and increasing body mass index on health-related quality of life and participation in society: a population-based cohort study from Sweden. *BMC Public Health*, 2014;14(1):381.
- Paper III Holmgren, M., Sandberg, M., Ahlström, G. The complexity of reaching and maintaining a healthy body weight – the experience from adults with a mobility disability. *BMC Obesity* 2018; In press.
- Paper IV Holmgren, M., Sandberg, M., Ahlström, G. To initiate the conversation – public health nurses' experiences of working with overweight and obesity in persons with mobility disability. Submitted 2018.

Papers I–III are available in open access, and the copyright belongs to the authors.

Introduction

Twenty-three years ago, I gave birth to my daughter. She was born with several severe disabilities. It was at that point I decided to become a nurse, because I wanted to deepen the knowledge and to understand the complexity of disability. Before I entered the nursing programme, her shunt broke, and I had to give all my trust to the personnel at the hospital. Due to a chain of several small incidents, and, from what I remember, miscommunication and lack of knowledge, she almost died. To be a next of kin has given me a close insight into several areas of disability. Together, experience in all these areas and being a nurse have given me the strength and knowledge to fight for her rights and to give her a voice and the right to live as everyone in the general population. Many years later, after the first occurrence of the broken shunt, the shunt broke again. I stood at half past three in the morning, refusing to leave the hospital, and argued for her rights to have a shunt fixed. This knowledge and experience may be useful to other people with disabilities or their next of kin, but it is not easy to share this with others, as a nurse or as a next of kin. My interest in research was born while studying for a master's degree in public health nurse education, interviewing parents of young adults with intellectual disabilities and public health nurses interacting with these young adults after their transition from habilitation to primary health care. In my eagerness to continue to understand the complexity in disability, I was searching for a project involving people with disabilities. I found a research programme whose purpose was to highlight the challenges of obesity in people with mobility disability (MD), which have not been given enough attention in Sweden. Avoidance of obesity is a challenge for many people and not least for those with MD. I applied for a doctoral position with this project, and the result is in your hand. I hope this can spread some light on this complex area and that these results can help people with disabilities and their next of kin.

Research has shown that a person living with disability faces challenges such as isolation, stigma and discrimination, and lack of access to health in everyday life (United Nations Human Rights, 2006). At some point in life almost everyone will temporarily or permanently experience difficulties in functioning (World Health Organization (WHO), 2011), that is, have MD. MD is experienced

differently from person to person in relation to their specific impairments, and therefore the challenges can vary widely. For people with spinal cord injury, traumatic brain injury and stroke, environmental barriers might be the greatest challenges (Hammel et al., 2015). For people with muscular dystrophy, it might be the fatigue and feebleness (Bostrom & Ahlstrom, 2004). People with fibromyalgia have described experiences not only of losses of jobs, hobbies and participation in social activities but also of stigmatization of the disease as challenging (Taylor, Adelstein, Fischer-White, Murugesan, & Anderson, 2016). However, the diagnosis of the disease alone does not explain what people with MD can do, what their prognosis is, what problems are most prominent and what their needs are (Geertzen, 2008). This thesis describes MD with a broad definition including many different impairments.

Background

Disability

Disability occurs when a person meets an inhospitable environment (e.g., inaccessible transportation inaccessible public buildings, limited social support, and negative attitudes) that does not interact with their functional ability or health condition (e.g. cerebral palsy, Down syndrome or depression) (WHO, 2018b). According to the International Classification of Functioning, Disability and Health (ICF), disability is an umbrella term for impairments, activity limitations and participation restrictions, reflecting a complex interaction between a person's impairments of bodily functions and the characteristics of their environment (WHO, 2002). The United Nations (United Nations Human Rights, 2006) states that persons with disabilities include 'those who have long-term physical, mental, intellectual or sensory impairments'. It also concludes that they may often face discrimination and barriers that restrict them from participating in society on an equal basis with others every day (United Nations Human Rights, 2006). The WHO (WHO) has acknowledged the difficulties in estimating disability in the population and reported data from two reports, The Global Burden of Disease and the World Health Survey (WHO, 2018b). In the global adult population aged 15 years and over, between 15% and 19.4% are estimated to live with some kind of disability, and between 2.2% and 3.8% are estimated to live with severe disabilities with no narrower definition (WHO, 2018b). In Sweden, the corresponding prevalence for those aged 16–84 years with any disability is 21%, and 7% have difficulties in functioning in terms of MD (Boström, 2008). Differences in definitions, inclusion criteria and assessment methods; differences in health services and habilitation; and differences in occurrence of underlying impairments may also be a reason that prevalence of disabilities varies across countries (WHO, 2011).

Disability incidence will also rise due to the aging population (WHO, 2011), with increased risk of chronic disease (Marengoni et al., 2011; WHO, 2011). A large part of the collective illness is found among people with disabilities, who also have lower education and worse financial situations compared to the general

population (Arnhof, 2008). Those with disability face greater barriers to accessing healthcare than those without disability (Horner-Johnson, Dobbertin, Lee, & Andresen, 2014; Krahn, Walker, & Correa-De-Araujo, 2015; Neri & Kroll, 2003), despite the right to equal access to healthcare (The Health and Medical Service Act (2017:30) (Hälsa- och sjukvårdslag 2017:30)).

Mobility disability

The greatest part of the reported illness in those with disability has been found among those with MD (Arnhof, 2008; Reichard, Stolze, & Fox, 2011), who also have greater unmet healthcare needs and access to care in comparison to those without MD (Mahmoudi & Meade, 2015). Higher age (Arnhof, 2008; Ferrucci et al., 2016; Okoro, Hollis, Cyrus, & Griffin-Blake, 2018), lower education and worse financial situation are also more common in people with MD, especially in women (Mahmoudi & Meade, 2015). MD is often described as a physical reduction in one or more of the body functions, arising from a congenital or acquired disease or injury (Region Skåne - Habilitation and Assistive Technology Services (Region Skåne - habilitering och hjälpmedel), 2018). A common definition of mobility disability (MD), in self-reported data on its occurrence, is the inability to walk at a moderate speed or to climb stairs (Boström, 2008; Chung, Demiris, & Thompson, 2015). People with MD are vulnerable individuals who more often than those without MD have additional long-term health problems such as pain, fatigue, depression, obesity and limited participation in society (Kinne, Patrick, & Doyle, 2004; Liou, Pi-Sunyer, & Laferrere, 2005; Rimmer, Chen, & Hsieh, 2011). Movement has been described by people with MD as strenuous and time consuming, often accompanied by anxiety and shame experienced in connection with the limited ability to move (Bostrom & Ahlstrom, 2004). Sometimes, movement has to be prioritized and well considered because of the restricted movement and lack of energy. The priority can be about doing what one wants to do or has to do or going for holiday (Ahlstrom & Karlsson, 2000).

Mobility disability, overweight and obesity

People with MD have overweight and/or obesity to a greater extent than people without MD (Lidstone et al., 2006; Liou et al., 2005; Oh et al., 2012; Reichard et al., 2011; Rimmer, Hsieh, Graham, Gerber, & Gray-Stanley, 2010; Rimmer,

Rowland, & Yamaki, 2007). In a Swedish report on health inequalities from 2008 (Boström, 2008) the results showed that 18% of adult men and women with any disability, were obese, with the highest prevalence seen in those with MD. At that point in time, 10% of the general population were obese in Sweden (Boström, 2008). There are only two studies investigating MD and weight in Sweden (Arnhof, 2008; Boström, 2008), both of which were cross-sectional studies. International statistics often report all disabilities as a whole, including all type of disabilities, and therefore there is a lack of statistics on MD and MD and overweight/obesity in combination. In the United States (US), the Center for Disease Control and Prevention (2017) reported that 36% of adults with any disability were obese in comparison to 23% among those without disability. Furthermore, obese adults with disabilities have diabetes, high cholesterol and hypertension to a greater extent than obese adults without disabilities (Froehlich-Grobe, Lee, & Washburn, 2013). Thus, studies are needed in Sweden on the prevalence of MD followed over time.

Overweight and obesity are associated with several diseases such as diabetes, hypertension, coronary heart disease and stroke (Bray & Bellanger, 2006; NCD Risk Factor Collaboration (NCD-RisC), 2016; WHO, 2017). In epidemiologic studies, degree of obesity is most often assessed by body mass index (BMI), which is an index used to classify underweight, normal weight, overweight and obesity. It is defined as the weight in kilograms divided by the square of the height in metres (kg/m^2). Weight classes are according to WHO's definition: underweight $<18.5 \text{ kg}/\text{m}^2$, normal weight ≥ 18.5 but $<25 \text{ kg}/\text{m}^2$, overweight ≥ 25.0 but $<30 \text{ kg}/\text{m}^2$ and obese $\geq 30 \text{ kg}/\text{m}^2$, (WHO, 2018a). Obesity is defined as a disease according to the International Classification of Diseases, 10th version (ICD10) (WHO, 2016). In 2016, the worldwide prevalence of overweight in adults was 39%, and the corresponding proportion for obesity was 13% (WHO, 2017), which is almost tripled since 1975. In Sweden, the prevalence of overweight in adults was 36%, and the prevalence of obesity was 15% in 2016 (Public Health Agency of Sweden (Folkhälsomyndigheten), 2016). Obesity and overweight are largely preventable conditions caused by an imbalance between energy intake and energy expenditure (WHO, 2017). Beyond the estimates of obesity, there are people who feel that public health messages focus too much on the physical health risks and weight loss and place too little emphasis on strategies to help those who find it difficult to manage obesity. People who have had weight problems since childhood and have struggled for a long time have described the complexity as more than 'eating less and exercising more' (Lewis et al., 2010). Complex situations in obesity prevention have also been described by people with MD, who reported that they put a higher priority on their social and emotional well-being than on prevention of obesity (Mudge et al., 2013).

Treatment and prevention in overweight and obesity

For prevention and treatment of overweight and obesity, evidence-based guidelines are available for adults (American College of Cardiology/American Heart Association Task Force on Practice Guidelines, 2014). However, none of these guidelines consider the needs of people with MD. The recommendations are based on evidence from systematic reviews of published medical literature and include both assessment of overweight and obesity and decisions about management based on the assessment. The assessment guidelines are important, as they give an indication of how prevention and treatment are conducted today. An example of a guideline's specific criteria for the assessment part is shown in Table 1.

Table 1.

A selection of guidelines for prevention and treatment of overweight and obesity in adult people (American College of Cardiology/American Heart Association Task Force on Practice Guidelines, 2014).

Measure weight and height and document in the medical journal annually
Assessment of weight and lifestyle history
Assessment and treatment of cardiovascular risk factors and obesity-related comorbidities
Assessment of need to lose weight
Advice to avoid weight gain and address other risk factors
Assessment of readiness to make lifestyle changes to achieve weight loss and identify barriers to success, and to determine weight loss and health goals and interventions strategies
Determine weight loss and health goals and interventions strategies
Weight loss option – comprehensive lifestyle intervention alone or with adjunctive therapies
Offer or refer for high-intensity comprehensive lifestyle intervention with options for alternative modes
Option for adding pharmacotherapy as an adjunct to comprehensive lifestyle intervention
Offer referral to bariatric surgeon if BMI >40 kg/m ² or if BMI >35 kg/m ² and at least one comorbidity is present
Weight loss maintenance and continue intensive medical management of cardiovascular risk factors and obesity-related conditions and periodic assessment of weight management options

In Sweden, the National Board of Health and Welfare (The National Board of Health and Welfare (Socialstyrelsen), 2017) have developed guidelines on living habits in general, including use of tobacco, use of alcohol, unhealthy eating habits and insufficient physical activity (PA). These national guidelines provide no specific Swedish guidelines on obesity prevention and treatment. The main recommendation for preventive work when it comes to overweight and obesity is to offer qualified health counselling in consultation. However, regional care programme for overweight and obesity is available as a governing document (Public Health Stockholm County Council (Stockholms läns landsting), 2016; Region Skane (Region Skåne), 2018b). These include recommendations for nutrition (National food agency (Livsmedelsverket), 2018) and regular PA

(FYSS - Evidence based knowledge (Evidensbaserad kunskapsbas), 2017) which is fundamental and strongly recommended in prevention and treatment of obesity (Shaw, Gennat, O'Rourke, & Del Mar, 2006; WHO, 2010).

For people with MD, healthy eating habits may be the primary strategy to control their weight (Center for Disease Control and Prevention, 2017), due to the difficulties in performing physical activity. Unhealthy eating habits are a likely contributing cause to overweight/obesity among people with disabilities, as food may be used as a consolation for sadness and boredom or as a consequence of loneliness or the strains of everyday life (Boström, 2008). In addition, unhealthy weight in people with disabilities may also be caused by too high intake of energy-dense food that is typically cheaper and easier to prepare (Drewnowski, 2004; Littman et al., 2015). Other reasons may be stress/depression (Littman et al., 2015) and fatigue and MD (Plow & Finlayson, 2012), which are related to a worse social situation. The reasons for this might be economic issues and/or social stigma related to the MD. To support individuals with MD who are overweight/obese, improving their eating patterns may therefore be more challenging compared to individuals without MD.

PA promotes good health and is defined as any bodily movement produced by skeletal muscles that requires energy expenditure (WHO, 2010). PA for adults includes recreational or leisure-time physical activity, transportation (e.g. walking or cycling), work, household chores, play, games, sports or planned exercise, in the context of daily, family and community activities (WHO, 2010). Together with nutrition, PA is one of the main strategies in treatment of obesity (Shaw et al., 2006; WHO, 2010), and the combination of nutrition and PA has shown greater results than nutrition alone (Shaw et al., 2006). PA reduces the risk of obesity-related disease, for example, high blood pressure and diabetes (Lackland & Voeks, 2014). WHO's recommendations (WHO, 2010) of PA for adults are at least 150 minutes of moderate-intensity aerobic PA, 75 minutes of vigorous-intensity aerobic PA or an equivalent combination of moderate- and vigorous-intensity activity per week. However, for people with MD, it is difficult to sustain regular PA, and facilitators need to address barriers to leisure-time activities (Learmonth & Motl, 2016; Martin Ginis, Ma, Latimer-Cheung, & Rimmer, 2016). Thus, PA is more complicated among people with MD, and the recommendations, which are not adapted to people with MD, therefore need to be adjusted (Rimmer et al., 2014; WHO, 2010). Several factors that hinder people with MD from participating in PA have been identified. A study by Newitt and colleagues (Newitt, Barnett, & Crowe, 2016) revealed that these factors included lack of walking balance, muscle weakness, pain, stiffness, bladder and bowel problems, depression and fear of injury. In addition, living with MD and pain for a long time can reduce participation in PA, as this often

brings a lack of energy, and decreased participation often brings an increased insecurity about how to exercise (Rimmer et al., 2010).

A framework to facilitate the adaptation of guidelines already used in the general population in groups with certain conditions has been developed in the US (Rimmer et al., 2014). The framework, GRAIDs (Guidelines, Recommendations, Adaptations Including Disability) is a rigorous framework developed through systematic reviews, expert panels and focus group interviews with people with disabilities and their family members. In the US, to facilitate implementing the promotion physical activity and healthful nutrition to people with disabilities, resources are available (Rimmer, Vanderbom, & Graham, 2016). However, little is known about the implementation of the guidelines in Sweden, which should therefore be investigated. Similar development and systematic adaptation of guidelines has not been done in the Swedish context, and therefore research is needed on how the guidelines are currently applied to people with MD in Sweden. Studies on whether and how the GRAIDs framework could be applied in Sweden might be one option to consider for the future.

Health-related quality of life

Measuring health-related quality of life (HRQoL) in a population gives insights into the nation's health and determines the burden of preventable disease, injuries and disabilities. This can be measured by several different instruments (Center for Disease Control and Prevention, 2000). HRQoL measures people's health in relation to their quality of life (QoL) (Center for Disease Control and Prevention, 2000), where health is described as 'a state of complete physical, mental, and social well-being and not merely the absence of disease, or infirmity', and important in the overall QoL (Center for Disease Control and Prevention, 2000). QoL is a multidimensional, subjective sense of well-being and covers physical, psychological, social and spiritual as well as objective status (Haas, 1999). There are several definitions of QoL (Felce & Perry, 1995); the WHO defines QoL as 'An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' ("The World Health Organization Quality of Life assessment (WHOQOL): position paper from the WHO," 1995). To measure a health problem's possible effects on QoL, HRQoL is used. HRQoL can therefore be defined as a measure of people's or groups' perceived physical and mental health (Center for Disease Control and Prevention, 2000) (Figure 1). Low HRQoL is often reported by people with MD (Drum, Horner-

Johnson, & Krahn, 2008; Horner-Johnson, Suzuki, Krahn, Andresen, & Drum, 2010) as well as by people with obesity (Ford, Moriarty, Zack, Mokdad, & Chapman, 2001; Soltoft, Hammer, & Kragh, 2009; Ul-Haq, Mackay, Fenwick, & Pell, 2013). Despite knowledge about the association of low HRQoL in both people with MD and in people with obesity, studies investigating the HRQoL in people who have a combination of both conditions are still sparse.

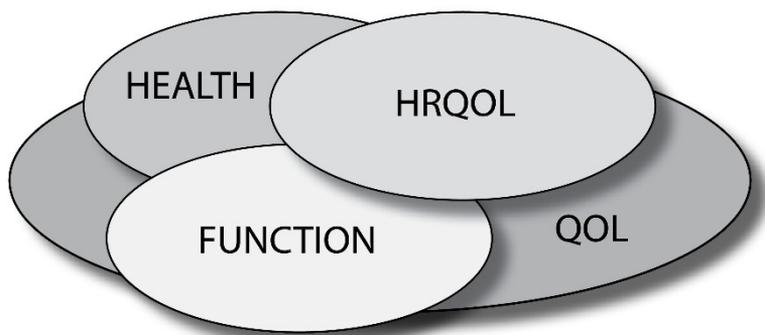


Figure 1.
The relation between health, QoL, function and HRQoL.

Participation in society

Participation is highlighted as a human right (United Nations Human Rights, 2006) and described as an individual's involvement in daily life (WHO, 2002). This means that all people, disabled or not, have the same rights and should have the same opportunities to participate. Participation in different aspects of social life is important for people with disabilities and in the field of disability research (WHO, 2002). In the ICF, nine domains describe participation: learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas and community, and social and civic life (WHO, 2001). In other words, participation can be regarded as everything that enables us to take part in society as independent individuals. In this broad and important area, several factors have been described as important in relation to participation among people with MD. Examples of these factors are health and function (Sundar, Brucker, Pollack, & Chang, 2016) and QoL (Chang, Wang, Jang, & Wang, 2012) as well as

proximity to recreational facilities, social support, transportation, neighbourhood security and user-friendliness of the walking environment (Levasseur et al., 2015). People with MD participate in society to a lesser extent than people without MD (Boström, 2008; Crawford, Hollingsworth, Morgan, & Gray, 2008; Gannon & Nolan, 2005) but have expressed that they would like to participate in society, that is, in work and leisure activities, to a greater extent than they do at the moment (Meulenkamp, Cardol, van der Hoek, Francke, & Rijken, 2013). Thus, because they are already at risk of lack of participation in society, there might be a further risk if people with MD also have overweight or obesity. As there is limited research on how to improve conditions and increase their opportunities to participate, more research is needed.

Public health policy

The Public Health Agency of Sweden has a national responsibility for public health issues. (Public Health Agency of Sweden (Folkhälsomyndigheten), 2018a). The Swedish national goal for public health policy is to create good and equal health conditions in the population with focus on, for example, living habits and healthcare that promotes equal health (Public Health Agency of Sweden (Folkhälsomyndigheten), 2018a). To be able evaluate this, national public health surveys have been conducted in Sweden in various forms since 1975 (Statistics Sweden (Statistiska centralbyrån)). Public health surveys give the opportunity to understand public health in the population and to follow changes in health over time as a part of the health policy follow-up (Public Health Agency of Sweden (Folkhälsomyndigheten), 2018b; Upmark, 2003). The public health surveys are performed jointly by the Public Health Agency and the county council, and Statistics Sweden (SCB) is responsible for the collection of data (Public Health Agency of Sweden (Folkhälsomyndigheten), 2018b). Each public health survey comprises parts that are the same in all county councils. It also includes a part that each county council can decide for themselves. This means that different parts in each survey could differ, for example, in age criteria (Statistics Sweden (Statistiska Centralbyrån), 2012). The random selection is drawn from SCB's National Population Register (Public Health Agency of Sweden (Folkhälsomyndigheten), 2018b). In Sweden, the national public health surveys are sent to respondents aged 16–84 years every second year. Every county council or region sends an introductory letter with the surveys to the inhabitants (Public Health Agency of Sweden (Folkhälsomyndigheten), 2018b), with information about voluntariness and confidentiality (Statistics Sweden (Statistiska Centralbyrån), 2012). The survey is send out by mail, but includes

an offer to conduct a web-based survey instead (Public Health Agency of Sweden (Folkhälsomyndigheten), 2018b). Since 2015, an English version has been available as a web survey. Altogether, two reminders are sent out.

Public health nurses

Health centres (HCs) are the primary care level where most of the population receive their care (Drevenhorn & Österlund Efraimsson, 2013). The HC is responsible for equality and for health prevention concerning living habits such as nutrition and physical activity (Region Skane (Region Skåne), 2018a). Several professionals such as public health nurses (PHNs), public health physicians, physiotherapists and dieticians, but also occupational therapists, curator/psychologists and midwives, may work at the HC (Drevenhorn & Österlund Efraimsson, 2013). Various professionals can be included in a team, depending on the patient's needs. PHNs have a central role in primary health care and in disease prevention and are often the health professionals that the patient encounters. (Swedish Association of Public Health Nurses (Distrikts-sköterskeförening i Sverige), 2008; WHO, 2018c). PHNs operate in a wide range of activities with knowledge in health promotion and health prevention at individual, group and societal levels for people of all ages at the HCs (Swedish Association of Public Health Nurses (Distrikts-sköterskeförening i Sverige), 2008). The PHNs' work at the HC can consist of nurse led clinics, including qualified health counselling in living habits and counselling by telephone (Drevenhorn & Österlund Efraimsson, 2013). PHNs are often team leaders in the work with diverse professionals who work with different patient groups. PHNs can also work both at community care and within schools, but regardless of the workplace, the PHNs have a distinctly health-promoting and disease-preventing perspective in their work (Swedish Association of Public Health Nurses (Distrikts-sköterskeförening i Sverige), 2008). The knowledge in communication and communication methodology that the PHNs have (Swedish Association of Public Health Nurses (Distrikts-sköterskeförening i Sverige), 2008) is very important in the PHNs' work.

Communication as a human-to-human relationship process is central to all nursing and has been described by the nursing theorist Travelbee (1971). The human-to-human relationship can be used to understand the interaction between the 'ill people' with MD in need of services of the PHNs, who have the knowledge and skills to assist the people with MD in their meetings. The human-to-human relationship is built over a long time, as the nurse interacts

with the ill person (with MD). Travelbee (1971) explained that *'a human-to-human relationship is established after nurse and recipient of her care have progressed through four preceding interlocking phases. These phases are 1) the original encounter, 2) emerging identities, 3) empathy and 4) sympathy. All of these phases culminate in rapport and the establishment of the human-to-human relationship'*. The term rapport is synonymous with human-to-human relationship (Travelbee, 1971), and all nurses know that they are supposed to have rapport with their patients (Travelbee, 1963).

Travelbee described how the first and important observations happen in the original encounter in a human-to-human relationship in the nursing process (Travelbee, 1971). It is through observation and communication that nurses ascertain the needs of ill people. The nurse must be able to understand the meaning of the ill people's communication, which can occur verbally but also non-verbally, through appearance, behaviour, posture, facial expression and gesture (Travelbee, 1971). There is always a sender and receiver in communications, and it is important that the message is understood by the people involved. The goal of the interaction in the communication is to know the ill people (with MD) to facilitate meeting the need for nursing and fulfil the purpose of nursing, and therefore, the nurse needs to know when or what to communicate in nursing (Travelbee, 1971). Even though the nurses have good skills in communications, the nurse can improve her skills through systematically studying the interactive process and learning more about what happened in the interaction, because the communication area is never completely learned (Travelbee, 1971). PHNs are sometimes the only health care professionals that people meet in the team at the HC. Therefore, good relationships in the communication between the people with MD (patients), and in this case, the PHN is important to optimize the interaction (Travelbee, 1971).

Rationale

As mentioned in the background section, people with MD are a group of people with higher prevalence of overweight and obesity and other obesity-related diseases compared to people without MD. They also have many different health problems, such as pain, fatigue and depression, to a greater extent than people without MD. This makes it difficult for people with MD to reach and maintain a healthy weight. However, epidemiological studies on the prevalence of MD and weight, differences between people with MD compared to those without MD as well as their associated HRQoL are still sparse in Sweden. Such research is necessary for understanding the health status of the whole population, including those with MD. In addition to nutritional changes in prevention and treatment of overweight and obesity, physical activity is strongly recommended to reach normal weight, which is difficult for people with MD.

Guidelines in overweight/obesity prevention and treatment for the general population are available along with a developed framework for adapting guidelines for the MD population. Despite this, general guidelines adapted to people with MD are missing in Sweden, and there is little knowledge on how any guidelines are used by PHNs and whether the PHNs adapt these guidelines by themselves. To be able to understand this, experiences from both people with MD and health professionals are needed, which could provide valuable information for how to implement guidelines in this population.

Because of the PHNs' great knowledge in health prevention and disease prevention, which is their main task in primary health care, the PHNs will become important in managing overweight and obesity prevention and treatment in people with MD. In addition, participation in society is important in the disability field and therefore important to investigate, if overweight and obesity further limits participation in society by people with MD.

Thus, the situation of people with MD in Sweden related to overweight and obesity has not given enough research attention. To define the problem, it is necessary to identify the prevalence of overweight and obesity in Sweden among people both with and without MD. Knowing the prevalence can help to identify any inequalities and adapt the guidelines for the general population to suit

people with MD. Knowledge and understanding of people with MDs' degree of participation with regard to their HRQoL in relation to overweight and obesity is necessary. Such awareness would assist in developing better health prevention strategies, which could lead to better overweight and obesity treatment and a healthier weight among people with MD.

Aims

The overall aim of this thesis was to investigate whether there is a negative association between overweight or obesity and HRQoL and participation in society among people with mobility disability (MD) in Sweden and to understand how people with MD and Public health nurses (PHNs) manage unhealthy weight.

Specific aims of the four studies were:

- I To investigate the BMI status and the association of overweight or obesity on HRQoL and participation in society among those with MD in comparison to those without MD.
- II To investigate mobility disability, overweight status, and obesity in a large population-based Swedish cohort of adults, and 2) to investigate whether mobility disability, high BMI, and increasing BMI over time are predictors of low HRQoL and lack of participation in society after 8 years of follow-up.
- III To explore the experienced importance of body weight among adults with MD and their possible paths to reaching or maintaining a healthy weight.
- IV To develop a substantive theory to explain the pattern in which PHNs manage adaptation of treatment and prevention guidelines to decrease overweight and obesity in people with MD.

Method

Design

This thesis is based on epidemiologic study design as well as qualitative study design to get a broad understanding about the association between overweight/obesity and MD according to HRQoL and participation in society, and management of prevention from the point of view of people with MD and PHNs (Table 2).

Table 2.
Overview of the studies included in the thesis

Study	Design	Sample	Data collection	Analyses
I	Cross-sectional	People from Skåne Public Health Survey (n=18,322)	Self-reported questionnaires on BMI, MD,HRQoL and participation in society in Skåne Public Health Survey, 2012	Descriptive analysis, interaction analysis and multiple binary logistic regression analysis
II	Longitudinal Cohort Study	People from Stockholm Public Health Cohort (n=13,549)	Self-reported questionnaires on BMI, MD,HRQoL and participation in society in Stockholm Public Health Survey, 2002 and 2010	Descriptive analysis using chi-square test and paired t-test, multiple binary logistic regression analysis
III	Qualitative	People with MD (n=20) from Skåne Public Health Survey	Semi-structured individual interviews, 2016	Content analysis
IV	Qualitative	Public health nurses (n=10) from Region Skåne	Unstructured individual Interviews, 2017	Grounded theory

Sample

Studies I and II were epidemiologic studies based on public health surveys (PHSs) conducted in Skåne and Stockholm regions, respectively, and collected by Statistics Sweden. Both studies used stratified random samples; in Study I, 18,322 respondents were included, and in Study II, 13,549. People both with and without self-reported MD were included in Studies I and II, while all people in Study III had this condition. MD was operationalized slightly differently in Studies I and II, due to differences in available questions and response alternatives in the two PHSs. In Study I the people stated that they were unable to run 100 metres in combination with being unable to either take one single step on a stair and/or take a short walk lasting approximately five minutes (n=667). In Study II, the people confirmed their MD by choosing one of the response alternatives: 'I have some problems in walking about' or 'I am confined to bed.' Because of the study's follow-up design and to avoid capturing temporary MD, respondents had to have given one of these questionnaire responses in both 2002 and 2010 (n=533). Details of drop-outs in Study I-II is shown in flow-chart, (Figure 2).

In Study III, people who had participated in Study I and had indicated an interest in receiving information about future studies were eligible for inclusion (n=403). An eligibility criterion was having had MD more than two years (n=20). They were selected because of their experiences and recruited with the aim of achieving balance in gender and distribution in age. Selection with variations in gender, age and weight (underweight/normal weight, overweight and obesity) was performed. An information letter about the study were sent to a total of 26 people with MD, who were then contacted by the researcher (MH) and asked about their willingness to participate. Twenty people with MD, 11 females and 9 males, aged 36–67 years, agreed to participate in Study III (Figure 2). Those contacted were people with MD who were aged 18–64 years at the time when the data were collected in 2012. Consequently, some people with MD had reached 67 years of age at the time for interviews.

Study IV included PHNs with experience of prevention work, including living habits and overweight and obesity in people with MD, who were recruited without discrimination in age and gender. The PHNs worked at HC settings in both urban and rural areas in Skåne County. In total, 10 PHNs at 10 different HCs were interviewed. There were 9 female PHNs and 1 male, aged 40–58 years and with experience as a PHN of 3–22 years (Figure 2). The PHNs were interviewed about people with MD, but no definition of MD was given during the interviews. Instead, they were allowed to 'define' MD by themselves and to talk freely about people that they thought had MD.

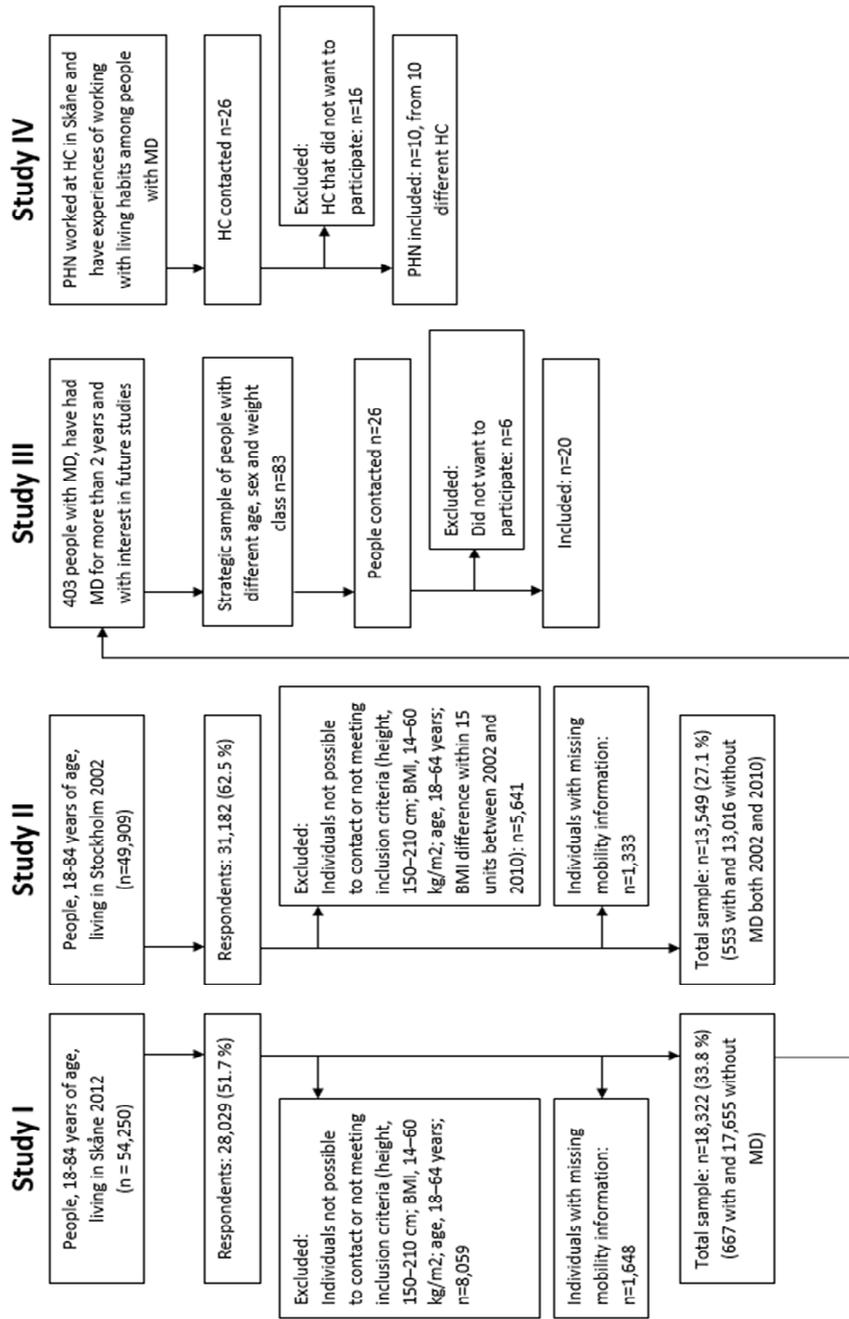


Figure 2. Flow-chart for drop-outs in studies I-IV

Data collection

Data from the PHSs were used in the two epidemiological studies. The data included questions about HRQoL and participation in society. Study I was a cross-sectional study based on the Skåne Public Health Survey collected between October 2012 and March 2013 by Statistics Sweden on behalf of Region Skåne. Study II was a cohort study based on the Stockholm Public Health Cohort collected in 2002 and 2010, also done by Statistics Sweden but on behalf of Stockholm County Council and in collaboration with researchers based at the Department of Public Health Sciences, Karolinska Institutet. The questionnaire in Study I was answered by 51.7% (28,029) of people who received it, and the questionnaire in Study II by 62.5% (19, 128). There were 18,322 people in Study I and 13,549 people in Study II who fulfilled the inclusion criteria and were included in the studies.

The interviews in Studies III and IV posed questions about the experiences of people with MD concerning their body weight (Study III) and experiences of PHNs regarding overweight/obesity prevention addressed to those with MD (Study IV). The interviews with all 20 people with MD in Study III were conducted between April and September 2016 at a place of their choosing, predominantly their own homes. In Study IV, the interviews with all 10 PHNs were conducted between September 2017 and February 2018, and all interviews except one were conducted at the PHNs' workplaces. One interview was conducted in a facility at Lund University. All interviews were performed by the author of this thesis.

Measurements of body mass index

In the PHSs, questions about weight and height were answered by all included people in Studies I and II, and the index was calculated by weight in kilograms divided by the square of the height in metres (kg/m^2) (WHO, 2018a).

Measurements of HRQoL

The PHSs that were used included different kinds of measurements. Studies I and II in this thesis are based on surveys that included single questions about health, and therefore, a selection was made of physically neutral questions including aspects of HRQoL through the domains of general health, mental health, pain, vitality and sleep problems. The domains were chosen after a

discussion between the authors of Study II and based on the domains that are common in various HRQoL measurements, such as the 36-item Short Form Health Survey (SF-36) (Sullivan, Karlsson, & Ware, 1995; Ware & Sherbourne, 1992) and EQ-5D (Center for Health Economics, 1990). All measurements, single questions and answer alternatives used in Studies I and II that are present below can be found in Appendix I.

Health-related quality of life

One common measurement in population studies (Matcham et al., 2014) is the SF-36 (Sullivan et al., 1995; Ware & Sherbourne, 1992). SF-36 includes questions about how people perceive their physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems and mental health (Sullivan et al., 1995). Studies I and II used the corresponding questions to measure HRQoL in the Skåne County Council and Stockholm County Council populations.

General health

The question on general health 'How would you rate your general health?' from SF-36 was used in Studies I and II. (Sullivan et al., 1995). The question had five possible answer alternatives from 'Excellent' to 'Very poor'.

Mental health

The General Health Questionnaire (GHQ-12) was used in Studies I and II to measure mental health. The 12-item GHQ-12 is a widely used self-reported instrument for detection of mental disorders in the community and non-psychiatric clinical settings, and has been used in several previous PHSs (Goldberg & Williams, 1988) GHQ-12 is a shorter version of GHQ-28, with comparable validity to the longer version, and has repeatedly been used as a screening instrument in population-based research (Goldberg et al., 1997). The measurement contains questions about experiences of a symptom or behaviour, where the respondent rates how common the symptom or behaviour has been during the last weeks on a 4-point scale (Goldberg, 2006). The answers were scored as 0 or 1 point per question, providing a maximum of 12 points, with a cut-off score of more than 2 considered as poor mental health.

Pain

Pain was measured in both Study I and Study II. In Study I, pain was measured based on the pain item in the EuroQol EQ-5D instrument (Center for Health Economics, 1990). EQ-5D is a standardized instrument used to measure

HRQoL. The instrument included questions about mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The people included in the study marked their current level of pain. Pain in Study II was based on three questions constructed for the Stockholm PHS about pain in the upper back or neck, pain in the lower back and pain in the shoulders or arms. A person who reported pain for more than a couple of days a week in at least one of the three questions was considered to have pain.

Vitality and sleep problems

Additional aspects of HRQoL were measured in Study I, which was not the case in Study II. In Study I the domains of vitality (from SF-36; (Ware & Sherbourne, 1992) and sleep problems were used. Vitality was measured using four items. Transformation of raw scale scores gave a range of 0–100 (Sullivan et al., 1995); scores were categorized as ‘low vitality’ or ‘high vitality’, using the mean value for the Swedish general population (68.8) as a cut-off (Sullivan, Karlsson, & Ware, 1994). Sleep problems were assessed by two questions about enough sleep and insomnia.

Participation in society

Participation in society was measured in both Study I and Study II and included social participation and participation in work. In Study I, social participation was measured through a 13-item question that measures how actively a person takes part in activities of formal and informal groups in society (Hanson, Ostergren, Elmstahl, Isacsson, & Ranstam, 1997). The people included in the study were asked to answer whether, during the last 12 months, they had participated in different kinds of activities. A cut-off score of ≤ 3 activities was considered as low social participation (Statistics Sweden (Statistiska Centralbyrån), 2012). In Study II social participation was measured with the question ‘In the past 12 months, have you more or less regularly participated in activities in society together with several other people?’ The dichotomous answer alternatives were ‘Yes’ or ‘No’.

Participation in work was measured in Studies I and II by one question about current employment.

Individual interviews

In Study III, 20 people with MD were interviewed. The interviews in Study III were semi-structured, using an interview guide. The interview guide was developed specifically for Study III and designed to capture the experience of people with MD concerning weight-related problems. The interviews were conducted as a dialogue (Kvale & Brinkmann, 2014). The interview guide included, for instance, questions about ideal weight and how the people felt about their weight in relation to MD, weight management and support from the HC. The number and formulation of follow-up questions depended on the richness of their answers to the main questions. Probing questions were typically designed to draw out more specific information, for example, 'In what way ...?', 'Can you give me an example of ...?', 'What kind of support ...?'

In Study IV, individual interviews were performed with a total 10 PHNs. Study IV was conducted as a grounded theory (GT) study in accordance with Glaser (1978). Data were collected by asking the PHNs questions about their work with prevention of overweight and obesity among people with MD, searching for a main concern. In GT, interviewing, analysing and coding occurs in an iterative process (Glaser, 1978, 1998). The first three interviews started with an open question: 'What is your experience of meeting persons with MD?' This was followed by 'What is your experience of treating obesity when you meet a person with MD?' and 'How would you work with consulting and tailoring health promotion programmes to people with MD?'

In accordance with Glaser (Glaser, 1978), memos were written throughout the analysis and generated the emergence of new questions, which were asked in the next three interviews. Examples of these questions were 'In what way is it difficult to discuss overweight and obesity with people with MD?' 'How does the discussion differ if the people have MD?' and 'How can you facilitate addressing the problem?' When the main concern and core concept emerged, questions related to these were asked during the final four interviews. Questions asked in these last interviews were such as 'I have understood that it can be difficult and sensitive to address weight problems with people with MD. Does that reflect your experience?' 'What determines whether you address the concern?' and 'Who has the responsibility for weight loss and being physical active?'

Analysis

Statistical analysis

Independent-sample t-tests were performed to compare BMI scores for people with MD and without MD (Studies I and II). Within-group changes in BMI between 2002 and 2010 were tested using paired t-test and in addition determined whether the group with MD showed greater increases in BMI than the group without MD (Study II). To analyse differences in frequencies (Study II), the study population were divided into six subgroups, those with MD and those without MD in three different weight classes: underweight/normal weight, overweight and obese. The differences between the six subgroups were analysed using the chi-square test (Study II). Mobility disability status and weight were also used in the regression analyses. In Study I, the regression analyses were based on groups with MD and without MD and weight classes – normal weight, overweight and obese – and the odds ratio (OR) was calculated as a comparison between these groups, whereas in Study II, the regression analyses were based on BMI, and OR was calculated for the outcome in every single variable. For each outcome (low general health, pain, low mental health and low participation) in Studies I and II, together with low vitality and sleep problems in Study I, ORs with 95% confidence intervals (CIs) were estimated using multiple binary regression analyses. Interaction terms between MD and body weight were included in the multiple binary regression model in Studies I and II.

For the multiple binary regression analyses in Studies I and II, dichotomous variables were created for MD (0=No; 1=Yes), general health (0=good; 1=poor/low), mental health (0=good; 1=poor/low) and pain (0=No pain; 1=Pain). In Study I further measured pain, using two dummy variables with no pain as reference (no pain vs. moderate pain, and no pain vs. extreme pain); vitality (0=high; 1=low) and sleep problems (0=no problems; 1=problems). Participation in work and society were reported separately in Study I, while participation in work and society were merged in Study II and reported as participation in society (0=High/Yes; 1=Low/No). In Study I but not in

Study II, all analyses were adjusted for the background variables gender, age, education level, marital status and country of birth. In Study II, instead, multiple binary regression analyses were performed to assess the impacts of specific variables (gender, age, MD, BMI in 2010 and change in BMI from 2002 to 2010). These were analysed one by one in backward elimination, investigating the impact on the likelihood of the people included in the study reporting that they had the specific outcome variables (pain, general health, mental health and participation). The regression analyses in Study II always retained gender and age, while using stepwise elimination of MD, BMI in 2010 and change in BMI from 2002 to 2010. In Study II, there were a large number of potential covariates, and therefore the order of the backward eliminations was determined using the Bayesian Information Criterion penalizing more complex models. Statistical analyses were performed using SPSS versions 21.0 and 22.0 (IBM Corp., Armonk, NY, USA) and R version 2.15.2 (Schwarz, 1978) in Study I.

Qualitative content analysis

In Study III, the interviews were analysed with qualitative content analysis in terms of a division into subcategories and categories, as described by Graneheim & Lundman (2004). Initially, the author of this thesis read each interview several times to get a sense of the whole. Meaning units were identified and then condensed and labelled with codes. These codes generated subcategories based on differences and similarities on a manifest level. The subcategories were then sorted into main categories. From the main categories and subcategories a main theme emerged, consisting of the interpretation of the wholeness of the content. The co-authors in Study III (Ahlström and Sandberg) read several of the interviews, all the meaning units and the subcategories, and independently discussed the codes, main categories and the theme with the author of this thesis. Finally, all authors discussed the categorization until consensus about the final results was reached. The 10th version of the NVIVO software (Edhlund & McDougall, 2013) was used as a tool for sorting of the text and establishing different levels of abstraction.

Iterative grounded theory analysis

Study IV was a GT study where interviewing, analysing and coding occurred in an iterative process in accordance with Glaser (1978, 1998). All 10 interviews were conducted by the author of this thesis. The analysis process started with processing the PHNs' narratives from the first three interviews, which were analysed by open coding of the PHNs' own words, line by line. (Glaser, 1978). The open coding of the first three interviews generated more refined interview questions.

Open coding conceptualizes the underlying pattern through empirical indicators within the data. During the analysis, questions were asked to the data and the narratives that are part of the open coding. In addition, memos are the interviewer's thoughts that occur during the analysis and were written throughout the analysis to capture new aspects and questions. Memos are a core component in GT.

After the first three interviews, next three interviews were performed with an analytical phase between them, when the raw data were coded. New questions emerged during the analytical phase that were used in the following interviews. The codes, generated from the concepts, were compared continuously during the analysis to confirm the relation between the data and the concepts. The core concept emerged through this constant comparison (Figure 3).

When the main concern 'To initiate the conversation' and the core concept 'Facilitate the process' emerged, the next phase of selective coding began.

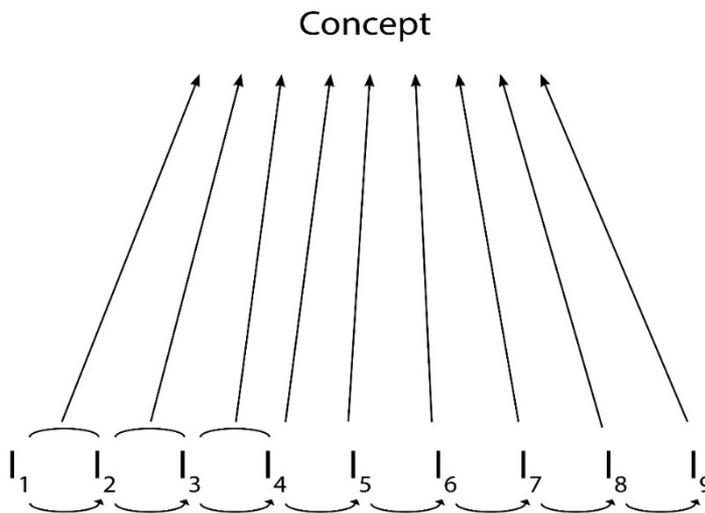


Figure 3.

The concept indicators model is based on a constant comparing of indicator to indicator and when a conceptual code is generated also comparing indicators to the emerging concept (Glaser, 1978).

The core concept explains how people included in the study resolve their main concern. Only those indicators that were related to the main concern in the phase of selective coding were included (Glaser, 1978). Therefore, questions related to the core concept and main concern were asked during the additional four interviews. This included refinement of questions until the data reached saturation. The co-authors of Study IV (Ahlström and Sandberg) read several interviews and reviewed the data to acquire an understanding of the data.

All authors continuously discussed the concern, concepts and categories until a consensus was reached. Saturation in the coding of the interview data was judged to have been achieved after nine interviews. This was assessed by the author of this thesis and was reviewed by the co-authors of Study IV. Furthermore, the interviewer made an additional interview with one nurse (interview number 10) that was analysed in the same way, but no new content emerged.

Ethical considerations

All studies (I–IV) were approved by ethical review boards. Study II was approved by Stockholm Regional Ethical Review Board and the Stockholm Public Health Cohort Steering Committee (Dnr: 2012/1193-31/5), and the Regional Ethical Review Board in Lund approved Study I (Dnr: 2013/897) as well as Studies III and IV (Dnr: 2015/773).

In research involving the participation of humans, it is important to consider the ethical guidelines for human research. The studies in this thesis followed the ethical principles of the Helsinki Declaration ("World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects," 2013) as well as ethical principles of respect for autonomy, beneficence and non-maleficence and the principle of justice (Beauchamp & Childress, 2013).

The principles of respect for autonomy

The principle of autonomy refers to a person's right to make choices taking action based on personal values and beliefs (Beauchamp & Childress, 2013). In Studies I–IV, the people included in the studies received an information letter about the purpose of the respective study, stating that participation was voluntary and including information about the confidentiality. Studies I and II were surveys collected by Statistics Sweden in collaboration with Region Skåne and Stockholm County Council, respectively. By answering and submitting the surveys, voluntary participation was confirmed. Studies III and IV were face-to-face interviews, and to ensure the principle of respect for autonomy, the people who participated in the study received oral and written information about the purpose of the study, so that they could make an autonomous decision to participate or not in the studies. Informed written consent was obtained before the participation began. All people who participated in the studies were informed that they had the right to withdraw from the project at any time without

explanation or consequences. Thus, all participation in the studies has been on a voluntary basis.

The principles of beneficence and non-maleficence

Beneficence refers to doing good to the people who participated in the studies, while non-maleficence refers to the risk of doing harm to those people. Benefits versus risks should be carefully weighed under this principle. Studies I and II used registers with encoded data, that is, data without personally identifying information. The unique codes linking each individual to her or his record in the analysed datasets were stored by Skåne County, Stockholm County Council and Statistics Sweden, respectively, and thus not available to the researchers. In Studies III and IV, the risk of doing harm to the physical health of people who participated in the studies in a short-term and long-term perspective was low, because of no physical engagement/activity. The risk of doing harm to mental health was low in Studies III and IV but considered in Study III, and therefore, the interviewer (MH) was extra careful and assisted the participants to contact a psychologist, if needed.

In Studies III and IV, questionnaires and interview data of the people who participated in the studies have been treated with confidentiality and kept anonymous for publication. Each person included in the studies was assigned a code number that was used for identification. A list of code numbers for the people who participated was kept in a locked cabinet and separated from the questionnaires and interviews. The recorded interviews were encrypted. In the interviews, the researchers were aware of power issues, in that an interview is not a conversation between two equal people. The people who participated were treated with the utmost respect, and every effort was made to be highly sensitive to their needs and wishes in order to not do harm. To maintain the principle of non-maleficence, the people who participated in the studies were guaranteed confidentiality (Studies I–IV). To guarantee confidentiality in Study III, fictitious name were used in the quotations. The deepened knowledge from the results in this thesis is beneficial to people with MD, related to facilitating a way to a healthy weight.

Results

The results from the four studies included in this thesis are presented in two main topics: HRQoL and participation in society (Studies I and II) and Narratives from different perspectives (Studies III and IV).

Characteristics of the study groups

The results from Studies I and II show that people with MD were more likely to be female, older and obese compared to those without MD. People with MD also had lower levels of education, were less often in work and more likely to have been born abroad. BMI distinguishes between the studies. In Study I, people with MD had a significantly higher BMI compared with people without MD (28.3 kg/m², SD 6.0 vs. 25.5 kg/m², SD 4.3, $p < 0.001$). In Study II, people with MD had a significantly higher BMI compared with people without MD (27.0 kg/m², SD 5.4 vs. 24.4 kg/m² SD 3.5) in 2002. The mean BMI was slightly higher for both groups in 2010, (with MD 27.7 kg/m², SD 5.9 vs. no MD 25.1 kg/m² SD 3.8). Furthermore, Study II revealed that there was a significant increase of BMI from 2002 to 2010 in the MD group vs. the no MD group (mean 0.6; 95% CI 0.4 to 0.9 vs. mean 0.7; 95% CI 0.7, 0.8). Both groups increased in BMI over time, but there was no significant difference between the increases (mean difference 0.08; 95% CI -0.2 to 0.3).

Outcome HRQoL and participation in society

General health

In Study I, interaction analyses revealed that the effect of obesity on general health was consistently and statistically significantly higher in people without MD compared to people with MD. There were no statistically significant effects

of overweight or obesity among people with MD. However, among those without MD, obesity was significantly associated with higher odds in general health in comparison to those with normal weight (OR: 2.62). In Study II, the descriptive analysis revealed that there were substantial differences between the weight groups in those without MD, meaning that more people who were obese and overweight perceived lower general health than those with normal weight (obese, 32.7%; overweight, 20.9%; and normal weight, 15.7%). A great proportion of people with MD perceived their general health as low, but the difference was smaller between the weight classes (obese, 85.0%; overweight, 84.6; and normal weight, 82.0%).

In Study II, the risk of obtaining low general health in 2010, after not reporting low general health in 2002, was higher in people with MD (OR 6.19; CI 3.93, 9.73) compared to people without MD, regardless of the level of BMI. In addition, the risk increased with an OR of 1.60 (CI 1.47, 1.74) for every 5 units of higher BMI in 2010. Furthermore, a BMI increase of 5 units from 2002 to 2010 increased the risk with an OR of 1.37 (CI 1.17, 1.62). For those with MD who reported low general health in 2002, the risk of retaining low general health in 2010 increased with an OR of 8.45 (CI 6.17, 11.84) compared to people without MD, regardless of BMI. The risk increased with an OR of 1.18 (CI 1.07, 1.31) for every 5 units of higher BMI in 2010. In addition, an increase to above average BMI or a decrease to below average BMI of 5 units, that is, away from 25 kg/m², both increased the risk with an OR of 1.23 (CI 1.08, 1.41).

Mental health

In Study I, no statistically significant effects of overweight or obesity on mental health were found among people with MD, but obesity (OR 1.19) was associated with higher odds among those without MD in comparison to normal weight. In Study II, the risk of obtaining low mental health in 2010, for those that did not report low mental health in 2002, was higher in people with MD (OR 2.77; CI 2.04, 3.72) compared to people without MD. Neither BMI nor an increase in BMI was significantly associated with low mental health. Similar results were found for those that reported low mental health in 2002. The regression analyses revealed that the risk of retaining low mental health in 2010 after reporting low mental health in 2002 increased with an OR of 3.00 (CI 2.22, 4.06) in people who reported that they had MD compared to people without MD. Here also, there were no significant associations between higher BMI in 2010 or increase of BMI and low mental health in 2010.

Pain

In Study I, interaction analyses revealed that the effect of overweight and obesity regarding moderate pain was larger among those without MD than those with MD. The interaction analyses also revealed that the effect of obesity in extreme pain was consistently and statistically significantly higher in people without MD compared to the people with MD.

In Study I, no statistically significant effects of overweight or obesity were found among people with MD. However, in people without MD, overweight (OR 1.24; CI 1.15, 1.33) and obesity (OR 1.79; CI 1.63, 1.97) carried an increased risk of moderate pain in comparison to normal weight, while overweight (OR 1.28; CI 1.03, 1.59) and obesity (OR 2.50; CI 1.60, 2.61) carried an increased risk of extreme pain in comparison to normal weight. In Study II, the risk of obtaining pain in 2010 after not reporting pain in 2002 was higher in people with MD (OR 2.98; CI 2.09, 4.22) compared to people without MD, regardless of level of BMI. A higher BMI in 2010 increased the risk with an OR of 1.12 (CI 1.05, 1.20) for every 5 units of higher BMI. The risk of retaining pain in 2010 after reporting pain in 2002 increased in people with MD with an OR of 4.51 (CI 3.48, 5.90) compared to people without MD, regardless of the change in BMI between 2002 and 2010. Five units of higher BMI in 2010 increased the risk with an OR of 1.14 (CI 1.05, 1.24).

Vitality and sleep problems

Vitality and sleep problems were only measured as domains of HRQoL in Study I. No statistically significant effects of overweight or obesity were found among people with MD. In people without MD, overweight (OR 1.14; CI 1.06, 1.22) and obesity (OR 1.70; CI 1.55, 1.88) carried an increased risk of low vitality in comparison to normal weight, and in relation to sleep problems, overweight (OR 1.13; CI 1.03, 1.24) and obesity (OR 1.47; CI 1.30, 1.65) carried an increased risk in comparison to normal weight.

Participation in society

In Study I, no statistically significant effects of overweight or obesity were found among people with MD. In people without MD, overweight (OR 1.16; CI 1.08, 1.25) and obesity (OR 1.43; CI 1.29, 1.58) were associated with higher odds for low social participation in comparison to normal weight, while obesity (OR 1.33; CI 1.20, 1.48) was associated with higher odds for not participating in

work in comparison to normal weight. In Study II, there was an increased risk for low participation in 2010 among those with MD who did not report low participation in 2002 (OR 3.88; CI 3.03, 4.95) compared to people without MD. The risk of retaining low participating in society in 2010 after reported low participation in 2002 increased with an OR of 2.97 (CI 1.98, 4.52) in people with MD compared to people without MD. The descriptive analysis showed higher frequencies of low participation in those with overweight and obesity compared to those with normal weight, independently of the MD. Neither BMI nor increases in BMI increased the risk of low participation independent of reporting low participation in 2002 or retaining low participation in society in 2010.

The narratives from different perspectives

Studies III and IV give the perspectives of people with MD and PHNs, respectively. In Study III, people with MD narrated their experiences of achieving and/or maintaining a healthy weight. In Study IV, the PHNs shared their experiences of working with health prevention regarding overweight and obesity, with the goal a healthy weight, in people with and without MD. In the results below, the narratives from Study III and Study IV are integrated.

The experiences of people with MD regarding the body weight's meaning in everyday life and their path to reaching and maintaining a healthy weight were captured in the theme *The complex trajectory to a healthy weight* (Study III). They saw everything as being connected. Irrespective of the specific nature of their own difficulties, of their own attempts to manage or of their own need for support, the problem they were confronted with was complex and needed to be properly understood. People with MD spoke of being in a vicious circle: problems that originated in their MD were exacerbated by the problem of overweight and obesity, which in turn exacerbated the other problems. The overweight or obesity exacerbated the MD and the pain, which affected the ability to exercise – and the lack of exercise affected the overweight or obesity. Even though the people with MD did not perceive overweight/obesity as the main problem, it was experienced as an extra burden on the body (mostly the legs). Support for people with MD who experience this complex situation could be facilitated by the PHNs, who reported that they worked closely with other professionals, such as physiotherapists and dieticians, and consulted their specific competence. The PHNs described the physiotherapist as an important resource

in giving recommendations for physical activities to people who had special needs such as MD and/or pain.

The people with MD in Study III spoke of how MD and pain often went hand in hand in a complex pattern of interconnected problems. They felt that it was not only the MD that limited their mobility but also their pain, which caused difficulty in exercising and restriction of their daily activities. Exercise can exacerbate both the disability and the pain. The PHNs in Study IV said that the physiotherapists were often the professionals with the experience to organize various kinds of group activities. Teamwork with both physiotherapists and dieticians was advocated by the PHNs, and they considered themselves as the key person in the team. However, the PHNs advocated group physical activity, due to the positive dynamics a group could have for people, but physical activity in groups was not offered as an obvious option at the HCs, to people with or without MD. As a way to diminish their workload, the PHNs offered suggestions about possible cooperation with private weight-loss companies, which could be subsidized as a treatment, nationwide sports federations and/or health coaches at the HCs (Study IV). However, this was not the wish of the people with MD who participated in Study III, for several reasons. Lack of money was mentioned by some people with MD as a factor affecting their ability to exercise. It was costly to use a gym, and even if the people with MD had the money, there remained both the problem of lack of help and support getting and being there and the problem of the gym's facilities not being designed for people with MD.

The people with MD in Study III talked about different strategies for reaching or maintaining a healthy weight. They spoke of how they tried to eat wisely, tried to exercise as best they could, tried to eat regular meals and tried to think long term. They had tried low-carb and other diets, and they had tried diet pills. Motivation was perceived by the people with MD as important, and they described this in terms of needing to have concrete targets (whether intermediate or final), such as the reduction of pain or simply being able to fit into their jeans again. Some people with MD did not see their overweight/obesity as a problem, and therefore, they were not motivated to reach a healthy weight. The PHNs in Study IV experienced that it was not always easy to motivate people, whether with or without MD. The PHNs related that it was important to keep up their own motivation and to continue to motivate all people, even though they felt that people with or without MD were unwilling to change their lifestyle. Some of the people with MD in Study III had firmly decided to reach a healthy weight or maintain their current healthy weight. These people talked about concrete strategies for reaching the target. They had obtained professional help from dieticians, they had set regular mealtimes and they had eaten moderate portions.

Long-term planning was described as an important factor with regard to reaching a healthy weight. Some people mentioned that they restricted their food intake because they could not exercise sufficiently. However, the PHNs in Study IV revealed that the dieticians often worked at several HCs, and it was common that they only worked once a week at the same HC. Close collaboration with other professionals such as physiotherapists, dieticians and physicians strengthens shared goals and perspectives in the work. This means that all in the team are giving the same advice to the people. People with MD in Study III who had positive experiences from the primary health care mentioned, for example, encouragement from the physician, good practical advice from the dietician, being treated in a friendly way and being offered follow-up meetings. However, when it came to wished-for required support, the people with MD spoke of the importance of a holistic approach, where physicians, nurses, physiotherapists and dieticians should all be involved. The PHNs in Study IV reported that they did not act differently whether they had people with or without MD in front of them; instead, they acted on an individual basis, aiming to adapt every meeting to the people's needs and conditions.

In Study III, the people with MD talked about their inner resources playing a significant role with regard to the attempt to reach or maintain a healthy weight. A significant role is to be assigned also to the person's awareness, motivation and attitude, as well as to his or her general thinking about the question of weight. People with MD were aware that weight gain was to be expected when one regularly used a wheelchair. They were also aware that if they ate more than their body consumed, they would increase in weight. In addition, the people with MD spoke of trying to look on the bright side, seeing challenges rather than obstacles.

In Study IV, the PHNs mentioned that there was a need for more time spending with people with MD to plan the adapted physical activity. Too little time with people with MD might hinder initiating the conversation about overweight or obesity. The PHNs talked about the need to 'feel out the situation' and trust and continuing contact with people were emphasized. By 'feel out the situation', the PHNs meant to interpret the individual's words and body language to determine whether it was possible to initiate the conversation or if there was an unwillingness to discussing overweight and obesity.

People with MD who participated in Study III emphasized that it was their own decision to reach or maintain a healthy weight, but it was not always easy, and they needed different forms of support. The PHNs in Study IV expressed that they have a responsibility to make people aware of their lifestyle and the risks of increased or new health problems, but they also expressed that, in the end, it was

the people's responsibility to change their lifestyle. However, the PHNs expressed the opinion that they had too little time for planning groups focused on lifestyle changes in regard to nutrition and physical activity together with the other professionals.

The PHNs stated that even though lifestyle changes are considered to be the first-hand treatment in overweight/obesity, it was still difficult to prioritize this in their everyday work. In Study III, the people with MD described their visions of what life would be like if they weighed less: easier movement with less stress on the joints, perhaps also lower blood pressure and lower cholesterol. They described both negative and positive experiences from the contact with the primary care and the specialist care regarding weight problems. Weight problems had in some cases been discussed at meetings with physicians, nurses, physiotherapists and dieticians, but some people with MD felt that their weight problems were not really discussed at all, in respect of either prevention or treatment. Some people with MD experienced that they were encouraged by the healthcare staff to lose weight, but without being offered any proper advice on how to do so. They also expressed that the staff evidently did not see them as being fat enough to need such advice, nor indeed see weight as a priority. In Study IV, the PHNs expressed that their own weight might influence how people received their advice, whether they were thin, overweight or obese. However, the PHNs mentioned that their own overweight or obesity could make it easier to initiate the conversation with people both with and without MD, because they could talk from their own concerns. The PHNs in Study IV experienced that initiating the conversation was facilitated when the overweight or obesity was related to medical issues such as high blood pressure, diabetes, respiratory problems or arthrosis. The PHNs also experienced that initiating the conversation was facilitated if the overweight or obesity and physical activity had been discussed before and recorded in the medical journal.

The people with MD in Study III who received treatment for diabetes and/or hypertension and had an established contact with the HC said that they had not been offered help to lose weight. They might have been offered help a long time ago, at the beginning of their illness, but not anymore. The PHNs in Study IV described their hesitation to initiate a conversation (the main concern) regarding overweight and obesity for being afraid of "offending anyone", and therefore, the PHNs did not initiate the conversation, regardless of whether the people had an MD or not. People with MD in Study III perceived the professionals as not having the competence to give such advice that met the needs of persons with MD. They expressed that the professionals had obvious problems in any situation when they attempted to offer advice. In addition, it was pointed out that a holistic approach should include specific knowledge about disability and

pain, including such things as correct exercise and nutritional advice from the perspective of pain. The people with MD in Study III experienced the lack of knowledge about the physical disability as a disappointment. However, the PHNs in Study IV described their prior experiences in contact with different people with MD as important. Even more important was extensive working experience, meeting all kinds of people, including working experience from other clinics or hospitals. Through years of experience, the PHNs learned to be sensitive in meetings with people to facilitate initiating conversations about sensitive topics. The PHNs learned to be sensitive in meetings with people that should facilitate initiating conversations about sensitive topics.

Discussion

The results in this thesis show that people with MD are overweight and obese to a greater extent than people without MD in Sweden. Even though BMI increased over time in people with MD, BMI did not increase more than in the general population. We found significantly lower HRQoL and lower participation in society in people with MD in comparison to those without MD. There were no additional associations with low HRQoL or low participation in society in people with the combination of MD and overweight or obesity (in terms of “double burden”). Even though, people with MD and co-existing overweight/obesity did not report lower HRQoL or participation, their experiences revealed that it was difficult to retain and maintain a healthy weight in relation to their problems, such as the MD itself, in terms of pain and difficulties in being physical active. In addition, the PHNs at HCs had difficulties in having a conversation about overweight and obesity, as this was experienced as a sensitive topic.

BMI over time

Results from two different counties in Sweden (Study I and Study II), showed higher BMI in people with MD, which is consistent with previous findings in the literature (Froehlich-Grobe et al., 2013; Lidstone et al., 2006; Oh et al., 2012). People with MD should therefore be prioritized in the obesity prevention strategies to avoid comorbidity with serious obesity-related illnesses. In addition, in Study II, people with MD did not experience a greater increase in BMI over time in comparison to those without MD. Contradictory results were shown in a similar study, where young men and middle-aged women with long-term MD increased more in BMI over time in comparison to those without MD (de Munter, Tynelius, Ahlstrom, & Rasmussen, 2016). One explanation for this could be different inclusion criteria compared to Study II. In the study by de Munter and colleagues (de Munter et al., 2016) eating disorder, depression, cancer, and schizophrenia within five years prior to baseline and during the study were excluded.

Health in relation to obesity

Since both MD (Drum et al., 2008; Thompson, Zack, Krahn, Andresen, & Barile, 2012) and obesity (Ford et al., 2001; Soltoft et al., 2009; Ul-Haq et al., 2013) are associated with low HRQoL, we expected to see an additional risk of low HRQoL when these two conditions coexisted (Studies I and II). Neither Study I nor Study II could reveal such association. The reasons for that might be the already increased risk of low HRQoL among those with MD, which has been reported in previous studies (Drum et al., 2008; Thompson et al., 2012). The type of MD might have importance. Salem and colleagues (Salem, Bamer, Alschuler, Johnson, & Amtmann, 2014) have investigated the association between obesity and HRQoL in people with MD (individuals with muscular dystrophy, multiple sclerosis, post-polio syndrome, and spinal cord injury) and in comparison to people without MD. Their results showed that obesity in people with MD is associated with lower HRQoL in comparison to people without MD. Within the disability group, obese people with muscular dystrophy and multiple sclerosis had lower HRQoL compared to those without obesity. This showed that obesity has an impact on HRQoL for some people with MD. The authors suggested that the differences between the outcomes for people with muscular dystrophy and multiple sclerosis might have to do with disability-specific features that can moderate the effects of obesity on HRQoL. They also mentioned that the differences were relatively small and may not be clinically significant. However, the obesity's impact within different MD groups needs to be further explored in future research in order to identify and tailor preventive measures. The diverse experiences of obesity on HRQoL within the MD group in Salem and colleague's study (Salem et al., 2014) and the absence of statistically significant associations between low HRQoL and the combination of MD and overweight/obesity in Studies I and II may be explained by the complexity found in Study III. The people with MD in Study III described their experiences of the relations between MD and overweight/obesity in negative terms (Study III). They talked about a vicious circle originating in the MD (Study III). They narrated that overweight and obesity could exacerbate the MD and the pain, which in turn could affect the ability to exercise. Pain is one part of HRQoL, and previous literature has shown that pain can be related to increased BMI (Stone & Broderick, 2012) as well as exacerbated MD (Plow, Moore, Husni, & Kirwan, 2014). It is known that chronic pain is a common secondary condition among people with MD (Kinne et al., 2004; Rimmer et al., 2011). Therefore, a professional's assessment and treatment of pain is an important routine to apply at HCs to facilitate design of person-centred preventive measures with the aim of preventing obesity and lower HRQoL.

The complexity of living well with MD has also been described by Nosek and colleagues (Nosek et al., 2004) as well as Mudge and colleagues (Mudge et al., 2013). In their studies, people with MD talked about multiple factors that influence living well, besides healthy food and physical activity. For example, psychological, social, and environmental factors were mentioned. This experienced complexity needs to be highlighted when working with health prevention for people with MD. Moreover, in Studies I and II, increased risk for lower HRQoL was seen among those without MD who were overweight or obese. They might increase their HRQoL if they were to lose weight. A recent systematic review showed that HRQoL was increased after weight loss to a greater extent after bariatric surgery (Kolotkin & Andersen, 2017). Even though this review did not draw conclusions regarding different subgroups such as people with MD, the review revealed that weight loss is of importance for HRQoL. This has to be kept in mind for future studies focusing on adapted prevention for people with MD, which will be discussed below. Thus, measuring HRQoL in people with MD before and after weight loss to further understand the obesity's association with HRQoL in those with MD could be an implication for future investigation.

Study II showed that people with MD perceived low participation in society in comparison to those without MD, which is in line with previous research (Boström, 2008; Crawford et al., 2008; Gannon & Nolan, 2005). For the long-term perspective, eight years' follow-up (Study II), people with MD have three to four times higher risk for low participation in society compared to those without MD, independent of whether they report low participation at the first measuring occasion or not. This may not be surprising because of the already known association between MD and participation in society (Boström, 2008; Crawford et al., 2008; Gannon & Nolan, 2005). However, the descriptive analysis reveals higher frequencies of low participation in those with overweight and obesity compared to normal weight. In addition, the regression analysis reveals that neither higher BMI nor an increase in BMI over time was significantly associated to low participation, independently of the MD. Results from a study Norrback, de Munter, Tynelius, Ahlstrom, & Rasmussen (2015) showed that obese people with MD participated less in social activities over time compared to people with normal weight and overweight. The contradictory results might have to do with different analysis methods or confounders, but indicate the importance of further investigating the body weight's association with participation in society to avoid further impact on already low participation for people with MD.

The importance of the interdisciplinary team in prevention intervention

The PHNs suggested that health care professionals such as physicians, nurses, physiotherapists, and dieticians should be included in the team for prevention at HCs and that this could possibly facilitate the patients' retaining and maintaining healthy weight. Such professionals could be those with such expertise in MD, pain, and weight management (prevention and treatment), requested by the people with MD (Study III). The PHNs remarked that physiotherapists were useful because of their expertise in movement and physical activity, especially for people with MD and/or pain. The PHNs explained that not all these professionals worked at the HC full-time, and therefore, this was a barrier. Working as a team has also been highlighted in a review of qualitative studies where health professionals, including exercise physiologists, occupational therapists, psychologists, physiotherapists, and health specialists, were mentioned as providing needed expertise in a health prevention programme (Newitt et al., 2016). In the literature, a broad range of professionals are included in different interdisciplinary teams managing weight loss, for example physicians, dieticians, exercise physiologists, and psychologists (Tapsell et al., 2017) as well as registered nurses/nurse practitioners, mental health workers, and dieticians (Osunlana et al., 2015). In addition, interdisciplinary teams in pain management have been reported to include, for example, physicians, registered nurses, physiotherapists, occupational therapists, and psychologists. The purpose of interdisciplinary teams is shared goal setting (Stanos, 2012), which is important among those people with MD, pain, and overweight/obesity. This has to be taken into consideration in the assessment of an interdisciplinary team for people with MD. In addition, it is important that the shared goal setting includes the people with MD; otherwise, no prevention or treatment will occur. The PHNs are often team leaders in the work with diverse professionals (Drevenhorn & Österlund Efraimsson, 2013) and could therefore be team leaders in interdisciplinary teams for people with MD. Despite effectiveness in weight loss (Tapsell et al., 2017), there are still challenges in implementing interdisciplinary weight management at HCs, and these challenges have recently been described in a qualitative study (Osunlana et al., 2015). The authors found the clinic environment to be a key factor, and they especially emphasized firm interdisciplinary relationships and communication as strategies to overcome the challenges. A Swedish study investigated implementation of lifestyle interventions at HCs and pointed at heavy workloads resulting in too little time for lifestyle counselling (Kardakis, Jerden, Nystrom, Weinehall, & Johansson, 2018). Even though this investigation did not focus on the interdisciplinary team, both lack of organizational support and lack of collaboration were mentioned in implementation of lifestyle interventions. However, PHNs as well

as other health professionals have a positive attitude and willingness to work with lifestyle changes and expressed a need to work with programmes to promote healthy lifestyles at HCs (Kardakis, Weinehall, Jerden, Nystrom, & Johansson, 2014). Thus, time, resources, and relationships/collaboration are necessary to implement weight management and/or lifestyles counselling for all people, and not least for those with MD.

The importance of communication skills

Insufficient communication was highlighted by both people with MD (Study III) and PHNs (Study IV) and has also been revealed as a problem in previous literature (Marrocco & Krouse, 2017). Those with MD reported that the health professionals did not initiate conversations about overweight or obesity, and the PHNs stated that they usually do not do this (Study III). The reason given was that it was a sensitive topic, and the PHNs were afraid of “offending anyone,” whether they were people with MD or those without MD. This fear has also been given attention in the previous literature, where both physicians and nurses have expressed difficulties in raising the sensitive topic of overweight and obesity with the patients (Blackburn, Stathi, Keogh, & Eccleston, 2015; Jansen, Desbrow, & Ball, 2015; Michie, 2007). This situation can be improved by the nursing theory by Travelbee, (1971), which describes how the first and most important observations happen in the original encounter in a human-to-human relationship in the nursing process (Travelbee, 1971). The process of observation is used to get to know the ill person as a unique human being and therefore is a necessary first step to developing a human-to-human relationship (Travelbee, 1971). During the phase of the original encounter, feelings about the other person are aroused, which is an important step in the verbal and non-verbal communications. The PHNs (Study IV) did not open up the conversation about such an important health issue as overweight or obesity, and thereby, the human-to-human relationship could not be reached. The PHNs mentioned “sensitive topic” as the reason for not opening up the conversation, which might be facilitated by more time and resources for the “observation phase.” Other studies have also found that more time and resources are needed to open up the sensitive topic of weight when weight is not directly associated with a medical condition (Blackburn et al., 2015; Hansson, Rasmussen, & Ahlstrom, 2011; Jansen et al., 2015). This is a clear indicator of a future initiative. Independent of whether the patient has MD or not, time and resources need to be more highly prioritized to manage the increased rate of people with obesity and thereby increased morbidity. In addition, more time is also needed for patients with MD because of adapted counselling. Further possibilities could be to have a multi-professional special prevention and

treatment unit intended for overweight/obesity including screening for all people with and without MD. The PHNs' qualifications and skills in communications and in supporting the quality of life in people with MD (Swedish Association of Public Health Nurses (Distriktssköterskeförening i Sverige), 2008), and the intention to continue to develop the communication skills and establish the rapport described by Travelbee (1963), might be openings in ongoing communications and thereby enable the next step in the human-to-human relationship that is emerging. Thus, more time, resources, and good communications skills are necessary in obesity prevention and treatment.

Adaptive guidelines

There are great possibilities in teamwork, shared goal setting together with people with MD, and adapted guidelines to overcome the communication problems. Even though health professionals would like to work in interdisciplinary teams, existing guidelines need to be adapted to people with disabilities such as MD. GRAID (Rimmer et al., 2014) has been developed by experts to facilitate the adaptation of healthy lifestyles and suggestions. An example of an adapted guideline is adaptation of the Diabetes Prevention Program, which recently has been tested among people with MD with promising results (Betts & Froehlich-Grobe, 2017). The Diabetes Prevention Program has proved that the programme can lower the risk for diabetes through weight loss and physical activity (Kramer et al., 2009; Kramer, McWilliams, Chen, & Siminerio, 2011). The programme was adapted with telephone meetings instead of personal meetings, physical activity tailored to the needs of people with an MD, nutrition and health guidelines for wheelchair users, and arm-based activity trackers instead of pedometers. This adaptation could be facilitating for the PHNs (Study IV) in the work with prevention and treatment of obesity, but cannot be realized without time, resources, and communication with the patients. The PHNs (Study IV) suggested weight-loss companies and/or nationwide sports federation could be enlisted as providers of subsidized treatment, but the people with MD experienced that the professionals at HCs themselves lack knowledge about nutrition and physical activity adapted to people with MD and the MD itself. In addition, the people with MD experienced barriers in using regular gyms because of the lack of help and support and reported that the gyms' facilities were not designed for people with MD. A first step to overcoming such barriers is the PHNs' application of adapted guidelines, which could support and facilitate participation of people with MD.

Even though the people with disability receive support and help from primary health care services, the habilitation in Sweden works as a complement when the society's fundamental resources are insufficient (Skåne & Region Skåne, 2016).

The habilitation's responsibility is to assist with the "special needs of knowledge." The fundamental knowledge about different disabilities, their consequences, and the treatment of people with disabilities is expected at the fundamental level in all organizations as well as in primary health care. This mean that the habilitation could, for instance, assist the health care service and thereby the PHNs and/or other professionals with respect to guidelines for prevention and treatment of overweight and obesity.

Methodological considerations

The purpose of research is to draw valid conclusions about the relations between variables (Kazdin, 2010). This thesis included four studies with four different designs, and for all studies methodological consideration have to be addressed to evaluate the strengths and weaknesses of the study results (Kazdin, 2010; Polit & Beck, 2012). Strengths and weaknesses for the quantitative Studies I and II will be assessed by internal and external validity, and for the qualitative Studies III and IV, trustworthiness will be assessed and discussed below.

Validity

Internal and external validity

Internal validity refers to whether the study design, conduct, and analysis answer the research questions without bias. External validity refers to whether the study findings can be generalized to other contexts (Kazdin, 2010). Factors other than the independent variable that may affect the results are called threats to internal validity and need to be taken into consideration. Thus, internal validity concerns the validity of inferences that the results reflect the true situation in the study and are not a result of chance, bias, or confounding. There are two fundamental threats to the internal validity, and these are history and maturation. History refers to the effect of events common to all subjects in their everyday lives, and maturation refers to processes changing over time that could explain the results, instead of the independent variable (Kazdin, 2010). This could be a threat to the internal validity in a cohort study.

All data in Studies I and II were assessed by self-reported measures on weight and height. It is known that people underestimate their weight and overestimate their height, resulting in less precise data compared to objectively measured data (Stewart, Jackson, Ford, & Beaglehole, 1987). In addition, the degree of

underreporting of weight increases with increasing body weight (Jeffery, 1996), which may result in underestimated prevalence of overweight and obesity. Furthermore, the BMI as a proxy measure of fat mass might be misclassified due to lower muscle mass among people with MD (Center for Disease Control and Prevention, 2018). All together, there is no other way to measure weight and height in PHSs, and the eventual misclassification is assumed to be approximately the same in other county councils and should therefore be comparable both over time and between the county councils.

History and maturation (Kazdin, 2010) could be threats to Study II because of its cohort design and the fact that it lasted over eight years, and changes related to this could have affected the results. In Study II the authors assessed that the risk of threat related to the risk of receiving MD between measurement points was low because MD was an inclusion criterion in both 2002 and 2010. The method of measuring BMI has not been adjusted over time and should therefore not threaten the history validity. However, being overweight or obese for a long time might imply an adaptation to one's weight. This could influence the HRQoL differently and thereby constitute a threat to the maturation. However, history and maturation threats should be similar to the compared groups with and without MD.

The SF-36 (Sullivan et al., 1995) and the EQ-5D (Center for Health Economics, 1990) are common and psychometrically tested measurements to measure HRQoL. These measurements include questions to measure physical functions, such as walking and climbing, which automatically give people with MD a lower score (Krahn, Fujiura, Drum, Cardinal, & Nosek, 2009). To measure HRQoL and compare the groups with and without MD, as in the PHSs in this thesis, the people with MD should automatically achieve a lower score. Using function-neutral measurements of HRQoL should therefore be preferable in people with MD (Krahn et al., 2009; Krahn et al., 2014). However, in this thesis, HRQoL was measured by looking at general health, mental health, and pain in Studies I and II, with the addition of vitality and sleep problems in Study I in line with the aim of using the most function-neutral measurements possible. This gives greater opportunities to investigate HRQoL independently of MD, which is a strength of these studies.

Through the stratified random selection in PHSs, the population in the strata has the same probability of being selected (Polit & Beck, 2012). Therefore, the people in Studies I and II should be representative of the populations in Skåne and Stockholm, which increases the external validity. In addition, Studies I and II include a large sample of people with and without MD from two different areas in Sweden. Study I included 18,322, of whom 667 had MD and Study II

included 13,549, of whom 533 had MD. Furthermore, analysis of the responses in Study I showed no significant difference in gender and weight, but differences in age and educational level. However, both Study I and Study II included more women than men, with similar frequencies. Study I had 10.4% more women than men, and Study II had 13.8% more women than men. Overrepresentation of women is not unusual in surveys (Ford et al., 2001; Soltoft et al., 2009). This means that the results from Studies I and II should not be a threat to the external validity and may therefore be generalized to similar populations in Sweden. In addition, the Nordic countries rate obesity as affecting 12%–18% of the population (Eurostat, 2017), and difficulty in walking as affecting 2.3%–5.6% (Norway not included) (Eurostat, 2014), which is similar to the results of this thesis. Further, the Nordic countries have a common historical, cultural and geographical background, which strengthens the possibility of generalizing the results in respect of these countries.

The data collection on two occasions in Study II confirms long-term MD, which was not the case in Study I, which only includes one occasion of data collection. However, the prevalence of MD in Study I (3.9%) corresponds to the sample of people with MD in Study II (3.6%). Even though Study I is a cross-sectional study and Study II a cohort study with long-term MD, the results are similar and may therefore be representative of the adult population with MD living in urban or rural areas of Sweden. One limitation that could be a threat to both external and internal validity is that the type of MD is lacking in Studies I and II. There is a possibility that people with severe diseases are more likely to not respond to surveys, which makes them underrepresented. As no information on severity or type of MD was collected, this cannot be controlled for in present studies.

Internal and external validity are important to assess the data in quantitative studies. In qualitative design, the assessment of the data is important as well, but other assessments are used. In accordance with the aim of presenting a whole picture of a situation, both quantitative and qualitative research is valuable. One example mentioned in the discussion about the internal and external validity is the lack of information about the severity of MD. However, deep knowledge can be acquired from qualitative studies about experiences of living with MD (severe or not) which will be assessed in terms of trustworthiness, which is discussed below.

Trustworthiness in terms of credibility, dependability, and transferability

Trustworthiness is often described in qualitative research, and is described according to Lincoln and Guba criteria (Lincoln & Guba, 1985) and in terms

of credibility, dependability, conformability, and transferability. This is explored for Studies III and IV as follows.

Credibility is an element of validity for qualitative research, and the method is used to capture the participants' experiences and opinions; it is the quality of the material that determines the credibility (Lincoln & Guba, 1985). A detailed description of the steps in the research process is a prerequisite to being able to assess the credibility.

The varied experiences within the group of people who participate in studies are important in qualitative studies based on content analysis to ensure credibility (Polit & Beck, 2012). Therefore, people with MD in Study III were chosen by variations in age, gender, and weight classes, as this could contribute to different experiences and hence increase the credibility of the study. The aim was to get a broad understanding of how people with MD handle their body weight in accordance with their own resources and strategies with regard to reaching and maintaining a healthy weight. In GT (Study IV), the credibility is a question of how well the pattern of data, that is, the concept, is covered in the interviews. Choosing PHNs working in large and small HCs, situated in both urban and rural areas, were the procedures undertaken to attain fit of the theory to the practice in general. Therefore, the PHNs in this study represented HCs of different sizes. This indicates that our findings may have a better fit with other HCs compared to studies in which the PHNs were selected from only one HC.

The number of people included in studies is not a main issue in qualitative research, and 20 people in Study III was deemed sufficient from the beginning, in accordance with the usual practice in studies designed for content analyses. In Study IV, the interviews continued until nothing new emerged, and saturation seemed to be reached after nine interviews; this was confirmed further after 10 interviews, which assessed the credibility. According to Creswell, (Creswell & Creswell, 2018) the sample size in qualitative research depends on the qualitative design, and 20–30 interviews are recommended in GT. This is certainly one approach to the sample size issue, whether another approach is equally doable. The idea of saturation in GT is that the collecting of data stops when the categories are saturated. This is when a sample is deemed to be adequate.

The length, and especially depth, of the narratives in the interviews is also important in qualitative research to judge the credibility in terms of believability of the interviews (Lincoln & Guba, 1985) in Studies III and IV. The length of the interviews in Study III was 27–99 minutes, and in Study IV was 33–66 minutes, and most of the interviews were rich with personal experiences, which were judged to have a sufficient depth. Moreover, the co-author G. Ahlström, who has a long experience of qualitative research, listened to the initial interviews

in Study III to ensure the quality of the interviews, and thereby the depth in the interviews, before the author of this thesis continued with further interviewing.

Credibility was also confirmed in Study III by means of the process being conducted by several experienced researchers (Denzin & Lincoln, 2005). The initial data were analysed by the first author and reviewed independently by two other researchers (Ahlström and Sandberg). Discussion of the findings took place in the form of an open dialogue between all authors, and they discussed the codes, the main categories, and the theme with the author. Finally, all authors discussed the categorization until a consensus about the final results was reached. In Study IV, during the process in which the pattern of the PHNs' concerns emerges, the concept in the GT that fits has to be relevant. The co-authors (Ahlström and Sandberg) actively participated in the process to ensure that the concept that fit was relevant. The co-authors' participation in the process also confirmed the integration (workability) of the concepts and modifiability. The objectivity and congruence between two or more independent researchers about the data's accuracy, relevance, or meaning refers to the credibility or conformability as the corresponding GT term (Glaser, 1998).

Another common way to strengthen the credibility is by using quotations from the participants' statements (Denzin & Lincoln, 2005), which was performed in Study III but not in Study IV. In Study IV, quotations should not contribute to further credibility because new concepts emerged and strengthened the process and trust during the iterative process. This means that quotations from the first interview should not mirror the results.

An interview guide was used in Study III, which means that the people included in the study were asked the same questions, which can therefore be replicated, increasing the dependability (Polit & Beck, 2012). The interview process is different in GT, with different questions being asked during the interviews. However, even in Study IV, the first three interviews used the same questions and can therefore be replicated and thereby have insight into the main concern. Also, valuations of coherence strengthen the dependability, which was the case in both Study III and Study IV, because three researchers discussed the interpretation of the results until consensus was reached. However, one limit in accordance with the dependability might be that each PHN in Study IV interpreted the definition of persons with MD from their own point of view. Therefore the PHNs' perceptions of MD may have influenced the results, which is at the same time a part of the aim with qualitative research.

The transferability in qualitative studies requires a detailed description of the people who participate, and the analytic process (Kvale & Brinkmann, 2014). Study III has a detailed description of people with MD, the data collection, and

the analytic process. Therefore, the experiences of people with MD have the possibility of being transferred to other groups of people with MD living in similar contexts. Transferability could also be strengthened by similar results from other qualitative studies even though the orientation is different. Other studies (Mudge et al., 2013; Nosek et al., 2004) have described complexity with regard to living with MD and its association to healthy weight, with findings similar to those of Study III in this thesis. However, in Study III there were a few people with a severe MD in the study group, and only two people with MD were permanent wheelchair users. On one hand, this may limit the transferability of the findings (Lincoln & Guba, 1985), but on the other hand, it reflects variations in the general population.

In GT the counterpart of transferability is modifiability, which describes how the theory, through the constant-comparative method, does not miss anything that fits into the theory. These criteria generate trust, and the general interpretation of Glaser (1998) was to make it possible to transfer the theory to a similar context through modifications by constant comparisons with new data for a new substantive area.

Conclusion

The findings of this thesis show that people with MD have lower HRQoL and participate in society to a lesser extent compared to people without MD. People with MD have a higher BMI compared to those without MD but an eight years follow-up did not reveal significant differences in increasing BMI over time between these groups, and people with MD did not increase more in weight than those without MD. Despite higher BMI (overweight or obesity), the combination of MD and overweight or obesity did not further decrease the HRQoL or participation in society. This means that this combination didn't generate a 'double burden' related to HRQoL and participation in society. However, those without MD, overweight and obesity have association to low HRQoL in some domains and low participation in society.

Even though overweight and obesity do not show a 'double burden' in terms of association to low HRQoL and low participation in society, the people with MD did speak of a complex situation in relation to MD and their weight. Co-existing MD and overweight/obesity exacerbate the MD and pain, which leads to difficulty in exercising and complicates the ability to reach or maintain a healthy weight. They tried to reach and maintain a healthy weight by themselves but needed support in this from the health care professionals, which requires

knowledge of MD and pain. The people with MD said that the health care professionals did not talk about weight management with them—or if they did, they did not take into account that the people with MD have MD.

On the other hand the PHNs spoke about the difficulty of initiating a conversation with people both with and without MD but with overweight or obesity. They experienced that overweight and obesity is a sensitive topic to raise with the patients. To open the door to a conversation about overweight or obesity, time and resources were needed, especially in the case of people with MD. The PHNs suggested the formation of an interdisciplinary team to assist people with MD in weight management. Both people with MD and the PHNs experienced that the prevention of overweight and obesity is not highly prioritized in health care.

Implications

- Because of the higher frequencies of overweight and obesity in people with MD they should be prioritized in the obesity prevention strategies to avoid co-morbidity. Evidence-based prevention programmes adapted to the needs of people with MD implemented by interdisciplinary PHC teams might become a valuable resource. PHNs could be the team leaders.
- Time and resources are a prerequisite to developing adapted health prevention for people with MD
- Knowledge about the MD population is also a prerequisite, and a cooperation between the HC and experts in the area of habilitation should facilitate the work with health prevention for people with MD.
- With regard to initiating a conversation about a sensitive topic, screening all patients in respect of overweight and obesity could be one solution, because in this situation no professional will be afraid of “offending anyone”. In addition, assessment and treatment of pain is an important routine to apply at the HC in order to be able to design person-centred prevention. In addition, screening-questions on how people experience their ability to move should specify the needs for adapted counselling. One suggestion should be to focus on a multi-professional special prevention and treatment unit intended for overweight/obesity.

- Both knowledge about the complex situation that people with MD experience and communication skills for sensitive topics could be an element in the public health nurse education.

Further research

The theory developed in this thesis needs to be tested whether the facilitators generated through the grounded theory are adequate or need to be adapted in order to open up a conversation about overweight and obesity in primary health care.

To further understand the impact of overweight/obesity impact on HRQoL in people with MD, research on weight loss in different groups of people with MD and the degree of overweight/obesity could be of value. An experimental study including measurement of HRQoL before and after weight loss in different MD groups could give more information about the association between HRQoL and weight.

Improvement of health prevention in the clinic needs evaluation and therefore studies in the area of adapted guidelines as well as implementation of interdisciplinary teams adapted to people with MD are of importance.

The contradictory results with regard to the impact of overweight/obesity on participation in society indicate a need for further investigation to better understand how overweight or obesity influences the participation of people with MD in society from different aspects.

Summary in Swedish

Personer med rörelsehinder ställs inför många utmaningar i sitt dagliga liv och den största andelen av den rapporterade ohälsan i befolkningen ses hos personer med rörelsehinder. Långvarig sjukdom är vanligt hos personer med rörelsehinder med smärta, depression, utmattning, och fetma vilket medför begränsad delaktighet i samhället. Den fysiska nedsättningen i en eller flera kroppsliga funktioner som personer med rörelsehinder upplever kan komma från en medfödd eller förvärvad sjukdom eller skada. Genom att mäta den hälsorelaterade livskvaliteten (HRQoL) hos personer med rörelsehinder och jämföra med personer som inte har ett rörelsehinder ges en uppfattning av hur de upplever sin hälsa. Forskning har visat att personer med rörelsehinder upplever sin HRQoL lägre än personer som inte har ett rörelsehinder. Detta gäller även personer med fetma som skattar sin HRQoL lägre än personer utan fetma. Kunskapen kring hur förhållandet är för de som har både rörelsehinder och fetma är ytterst begränsad.

Övervikt och fetma är ett snabbt ökande folkhälsoproblem i världen med många sjukdomar som är direkt kopplade till fetma. Ungefär 39 % i världen har övervikt och 13 % har fetma vilken är nästan en trefald ökning sedan 1975. I Sverige beräknas att 36 % har övervikt och 15 % fetma. Eftersom fetma ökar risken att drabbas av bland annat kranskärslsjukdom, högt blodtryck, diabetes, stroke och vissa former av cancer är det viktigt att arbeta både förebyggande och behandlande för att minska utbredningen av övervikt och fetma. I denna avhandling definieras övervikt och fetma genom Body mass index (BMI) som är vedertaget mått som används för klassificering av kroppsmassan enligt följande; undervikt $<18.5 \text{ kg/m}^2$, normal vikt ≥ 18.5 till $<25 \text{ kg/m}^2$, övervikt ≥ 25.0 till $<30 \text{ kg/m}^2$ och fetma $\geq 30 \text{ kg/m}^2$. BMI räknas ut genom att kroppsvikten i kg divideras med längden i meter² (exempel; $60\text{kg}/1,652=22$).

Flera studier har visat att övervikt och fetma är mer vanligt hos personer med rörelsehinder än hos den övriga befolkningen. Eftersom övervikt och fetma orsakas av en obalans mellan intag och förbrukning av energi blir kost och motion de främsta parametrarna när det gäller både att förebygga övervikt och fetma men också när det gäller att behandla fetma. Studier har visat att det är mer komplext än att bara 'äta mindre och röra sig mer'. För personer som har

svårt att röra sig minskar förutsättningarna till fysisk aktivitet och då blir kosten desto mer viktig. Personer med rörelsehinder har många gånger både sämre ekonomi och sämre ork att laga mat och då ökar risken att kosten blir näringsfattig och kaloririk eftersom sådan kost är både billigare och lättare att tillaga. Sveriges nationella mål för folkhälsa är att skapa en god och likvärdig hälsa hos befolkningen med bland annat fokus på goda levnadsvanor vilket ger förutsättningar att uppnå hälsosam vikt. Det finns riktlinjer som är vetenskapligt framtagna för att främja hälsosam vikt och därmed minska övervikt och fetma hos befolkningen. Rekommendationerna betonar fysisk aktivitet och för att fysisk aktivitet ska vara möjlig för personer med rörelsehinder behöver den anpassas till deras förutsättningar att vara fysiskt aktiva. Aktuell forskning om hur riktlinjer kan anpassas till personer med rörelsehinder saknas i Sverige. Primärvården i Sverige har ett ansvar att arbeta både förebyggande och behandlande när det gäller övervikt och fetma samt att detta fungerar på ett optimalt sätt även för personer med rörelsehinder. Distriktssköterskan är en av de olika professionerna som arbetar med prevention på vårdcentralerna i Sverige och är oftast den person som möter patienterna kontinuerligt.

Syftet med denna avhandling var att undersöka om övervikt eller fetma påverkar den hälsorelaterade livskvaliteten (HRQoL) och delaktigheten i samhället hos personer med rörelsehinder i Sverige och att generera kunskaper som ökar förståelsen av hur personerna med rörelsehinder och distriktssköterskorna hanterar ohälsosam vikt.

Avhandlingen omfattar fyra delstudier med kvantitativ eller kvalitativ ansats. I studie I och II användes data från folkhälsoenkäter som besvarats av personer med och utan rörelsehinder. Studie I var en tvärsnittsstudier och data från invånarna i Skåne samlades in 2012 och studie II var en kohortstudie från Stockholm som samlades in 2002 och 2010. Både i studie I och i studie II användes insamlad data som kunde besvara frågeställningar om BMI och uppfattad HRQoL och i vilken omfattning befolkningen var delaktig i samhället. I de statistiska analyserna jämfördes personer med rörelsehinder med de utan rörelsehinder. Dessutom undersöktes om personer med rörelsehinder och övervikt eller fetma upplevde sin HRQoL och delaktighet i samhället som "en dubbel börda". Resultaten från dessa studier visade att personer med rörelsehinder har ett genomsnittligt högre BMI i jämförelse med de som inte har rörelsehinder. Resultatet visade också att BMI:et ökade i båda grupperna mellan 2002 och 2010 men det fanns ingen skillnad i ökningen mellan grupperna. Resultaten visade också att personer med rörelsehinder upplevde sin HRQoL lägre och deltog i samhället i lägre utsträckning i jämförelse med personer utan rörelsehinder. Trots det så upplevde personer med rörelsehinder inte att det var "en dubbel börda" att ha både rörelsehinder och övervikt/fetma när de skattade

sin HRQoL eller delaktighet i samhället. Personer utan rörelsehinder däremot upplevde att övervikt eller fetma gav dem lägre HRQoL i vissa domäner och lägre delaktighet i samhället.

Studie III och IV var kvalitativa studier. I studie III intervjuades 20 personer med rörelsehinder i Skåne om sina upplevelser kring kroppsviktens betydelse i kombination med sitt rörelsehinder och vilka strategier de använde sig av för att bibehålla eller återfå en hälsosam vikt. Intervjuerna utfördes mellan april och september 2016 i Skåne och analyserades med innehållsanalys. I resultatet framkom att personerna med rörelsehinder upplever sin situation med rörelsehinder relaterat till sin vikt som en ond cirkel svår att ta sig ur. Både rörelsehindret i sig men också smärtor beskrevs som hinder till att motionera eller röra på sig och utan motion blir det svårare att hålla vikten. Dessutom förvärrar motion/träning dels rörelsehindret och dels smärtan vilket gör det svårare att motionera och därmed att hålla vikten. De personer som intervjuades berättade också om olika strategier de hade för att bibehålla eller återfå en hälsosam vikt. Både äta mindre helt enkelt och olika dieter framkom som strategier. De berättade också att personalen på vårdcentralen sällan lyfte problemet med fetma men när de gjordes framkom att personerna med rörelsehinder inte upplevde att de blev förstådda. Personerna med rörelsehinder önskade att personalen på vårdcentralen hade större förståelse och hade mer kunskap kring rörelsehindret och därigenom kunde anpassa rådgivningen om kost och motion.

I studie IV intervjuades 10 distriktssköterskor från olika vårdcentraler i Skåne under perioden september 2017 och februari 2018. I studien användes GT (grounded theory) som metod vars syfte är att upptäcka det gemensamma problem som finns kring ett specifikt ämne och att skapa en teori för att lösa problemet. Resultatet som framkom i denna studie var att distriktssköterskorna hade svårt att öppna upp för samtal kring övervikt och fetma eftersom det upplevdes som ett känsligt ämne och distriktssköterskorna vill inte såra någon. De berättade också att de inte gjorde någon skillnad om patienten hade rörelsehinder eller inte utan anpassade samtalet utifrån vilken patient de träffade. För att lösa problemet med att initiera ett samtal framkom olika lösningar som skulle underlätta för att öppna upp samtalet. Tid, resurser och samarbete mellan de olika yrkeskategorierna som arbetar på vårdcentralen lyftes fram som mycket viktiga. Distriktssköterskorna berättade också att det var mycket lättare att öppna upp samtalet kring övervikt och fetma om de hade något att koppla övervikten/fetman till som t.ex. om patienten hade diabetes. Dessutom så tyckte de som jobbat med diabetes att det var lättare att ta upp problemet för att de hade vana att prata om kost och motion.

Sammanfattningsvis visar studierna att personer med rörelsehinder upplever sin HRQoL lägre och deltar i samhället i lägre utsträckning än personer som inte har rörelsehinder. Personer med rörelsehinder har övervikt eller fetma i större utsträckning än personer utan rörelsehinder och ett utökat stöd med anpassad rådgivning om kost och motion skulle kunna underlätta för dem som önskar rådgivning för att kunna behålla sin hälsosamma vikt eller återfå den. Detta stöd skulle kunna ges av distriktssköterskorna på vårdcentralen som i teamarbete med andra yrkeskategorier på vårdcentralen skulle ha möjlighet att stärka rådgivning anpassad till personer med rörelsehinder. För att detta ska fungera behövs både tid, resurser och kunskaper inom området rörelsehinder. Ett samarbete med rehabiliteringen skulle kunna bidra med ökade kunskaper från ett funktionshinderperspektiv.

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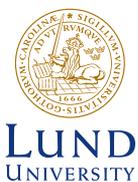
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Appendix I



Appendix I. Measurements and questions used in study I and II in this thesis.			
Measurements	Question	Answer alternatives	Scoring
SF-36, general health	How do you rate your general health?	Excellent/ Very good/ Good/Poor /Very Poor	Poor and very poor considered to be poor/bad health
GHQ12; <i>Have you recently:</i>	Been able to concentrate on whatever you're doing?	Better than usual/ Same as usual/ Less than usual/ Much less than usual	0-1 point per question, maximum 12 points. Cut-off score of more than 2 considered as poor mental health
	Lost much sleep over worry?	Nor at all/ No more than usual/ Rather more than usual/ Much more than usual	
	Felt that you are playing a useful part in things?	More so than usual /Same as usual/ Less useful than usual / Much less useful	
	Felt capable of making decisions about things?	More than usual/ Same as usual/ Less so than useful/ Much less capable	
	Felt constantly under strain?	Nor at all/ No more than usual/ Rather more than usual/ Much more than usual	
	Felt you couldn't overcome your difficulties?	Nor at all/ No more than usual/ Rather more than usual/ Much more than usual	
	Been able to enjoy your normal day-to-day activities?	More so than usual/ Same as usual/ Less so than usual/ Much less than usual	
	Been able to face up to your problems?	More so than usual/ Same as usual/ Less able than usual/ Much less able	
	Been feeling unhappy and depressed?	Nor at all/ No more than usual/ Rather more than usual/ Much more than usual	
	Been losing confidence in yourself?	Nor at all/ No more than usual/ Rather more than usual/ Much more than usual	
	Been thinking of yourself as a worthless person?	Nor at all/ No more than usual/ Rather more than usual/ Much more than usual	
	Been feeling reasonably happy, all things considered?	More so than usual/ About same as usual/ Less so than usual/ Much less than usual	
EQ-5D;	Mobility	I have no problems in walking about/ I have some problems in walking about/ I am confined to bed	I have some problems in walking about or I am confined to bed was considered to be defined as MD
	Self-Care	I have no problems with self-care/ I have some problems washing or dressing myself/ I am unable to wash or dress myself	
	Usual Activities	I have no problems with performing my usual activities/ I have some problems with performing my usual activities/ I am unable to perform my usual activities	
	Pain/Discomfort	I have no pain or discomfort/ I have moderate pain or discomfort/ I have extreme pain or discomfort	No Pain/ Moderate pain/ Extreme pain
	Anxiety/Depression	I am not anxious or depressed/ I am moderately anxious or depressed/ I am extremely anxious or depressed	

Pain	Have you during the last 6 months had pain in the upper back or neck?	No, never/ Yes, a couple of days / Yes, a couple of days a month/ Yes, a couple of days a week/ Yes, every day	Pain was considered if the participant had pain for more than a couple of days a week in at least one of the three questions.
	Have you during the last 6 months had pain in the lower back?	No, never/ Yes, a couple of days / Yes, a couple of days a month/ Yes, a couple of days a week/ Yes, every day	
	Have you during the last 6 months had pain in the shoulders or arms?	No, never/ Yes, a couple of days / Yes, a couple of days a month/ Yes, a couple of days a week/Yes, every day	
SF-36 vitality; How much of the time during the last seven days	Did you feel full of pep?	All of the time/ Most of the time/ A good bit of the time/ Some of the time/ A little of the time/ None of the time	Scoring 0-24 points. Low or high vitality was considered
	Did you have a lot of energy?		
	Did you feel worn-out?		
	Did you feel tired?		
Sleep problems from two questions	Do you think you get enough sleep to feel rested?	Yes, often/ Yes, but not enough/ No, never or almost never	Those who had answered 'No, never or almost never' were considered to have sleep problems.
	During the past 14 days, have you had trouble with insomnia or sleeping badly; and of so, to what extent?	Yes, quite often/ Yes, a little / No	Those who had answered 'yes, quite often' were considered to have sleep problems.
Social participation	<i>Study I:</i> Have you during the past 12 month had;	Participated in a study circle/course at work /Participated in a study circle/course in your spare time/ Participated in a union meeting/ Participated in meeting of an association/ Been to the theatre/cinema/ Visited an art exhibition/ Participated in a religious service/ Been to a public sports event/ Written a letter to a newspaper/magazine/ Taken part in a demonstration of some sort/ Visited a place of public entertainment (e.g., night club, dance, etc.)/ Taken part in a large family gathering/ Been to a party at someone's home.	≤3 activities was considered as low social participation
	<i>Study II:</i> In the past 12 months, have you more or less regularly participated in activities in society together with several other people?	Yes/ No	No = No participation in social activities
Participation in work	<i>Study I:</i>	In work/ Approved absence/parental leave/ Studying or in training/ Measure for entering labour market/ Unemployed/ Retired/ On disability pension/ On long-term sick leave	Working, but formally absent from work or on parental leave, and/or studying were defined as participation in work
	<i>Study II</i>	In work/ Approved absence or parental leave/ Studying or in training/ Unemployed/ Retired/ On disability pension/ Take care of the household	Working, but formally absent from work or on parental leave, and/or studying were defined as participation in work



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