

## RESEARCH ARTICLE

# Experiences of quality of life in people with Multiple Sclerosis who are in a wheelchair

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**Abstract**

**Aim:** The study includes health-related quality of life for people in Norway with multiple sclerosis who live at home and are in a wheelchair ( $N = 6$ ). The purpose is to show how they experience living with a chronic disease such as MS and how they perceive their own situation. How they value their own health and what leads to positive consequences is central to this study.

**Design:** The study has a qualitative design to show what health-related experiences they had while living with MS.

**Method:** The interviews were conducted in their home and later transcribed. An interview guide with open-ended questions was used. The transcribed material was analysed with a thematic analysis.

**Results:** Key themes were being free and independent, threat to the self and one's identity, and adaptation to MS. Free and independent in everyday life was essential for all the informants. Being dependent on others for basic needs was something they sought to avoid. Adapting to the new situation of changing roles was a challenge that required a lot of them.

**KEYWORDS**

chronic disease, multiple sclerosis, quality of life, wheelchair

## 1 | INTRODUCTION

Multiple sclerosis (MS) is one of the most complicated neurological disorders that affects all parts of patients' lives, and for many causes a reduced quality of life (Kędra & Wilusz, 2016). In Norway, more than 10,000 people live with MS, the prevalence of the disease is increasing rapidly, and Norway has the highest incidence in the world (Berg-Hansen et al., 2014). MS mainly affects people between the ages of 15 and 40 (Berg-Hansen et al., 2014). Although the course of MS is very different for patients, many experience challenges related to physical (e.g. fatigue), cognitive (e.g. memory and concentration) and mental disorders (e.g. depression and sadness)

(MS Association, 2019). This means that many patients beyond the course of the disease can no longer be in permanent employment and may lose opportunities to participate in social relationships (MS Association, 2019).

There has been a gradual shift in MS research aimed at medical treatment (MS Association, 2019). Previous research is actively working to find the causes of the disease and which treatment is most effective. Nevertheless, it seems that there is a need for more systematic knowledge about quality of life in connection with patients' experiences, their challenges and what can be helpful when they live in their own home (Riazi et al., 2012). How people living with MS experience quality of life has been studied in several contexts. Riazi et al. (2012) interviewed 21 people who had MS and who

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lived in nursing homes about their quality of life. They found that several people believed that living in a nursing home could relieve the family and that it created security by having an adapted environment. Nevertheless, there were several who experienced isolation and difficulties in adapting to life in an institution. Accessing rehabilitation built up a sense of independence for people with MS (Riazi et al., 2012). Furthermore, Muzo-Dutton et al. (2012) found after interviewing 12 people with MS in hospital that the diagnosis did not lead to loss of self, but a changed "self." These changes represented a negative impact on mood and psychological function (Mozo-Dutton et al., 2012). Giovannetti et al. (2017) found when they interviewed 19 people with MS that the disease received most of the attention in everyday life, while well-being came in the background for the disease focus.

### 1.1 | Quality of life and MS patients

Quality of life is a broad concept and encompasses several aspects of a person's life. Gabrielsen (2012) describes quality of life when a person is active, has cohesion, has self-esteem and has a basic mood of joy. Furthermore, Aggernæs (1988) describes that people have a quality of life when they have covered the elementary biological needs, have human contacts, meaningful employment and have a varied, exciting and engaging shopping and experience life. Maslow (1970) also shows the importance of people meeting basic needs such as physiological, security needs, love and belonging, respect, appreciation and self-actualization. When people get a chronic disease such as MS, these needs can be negatively affected so that this overall reduces people with MS' quality of life. Smedema and Bhattarai (2021) points out that the strongest character strengths that affect quality of life in people with MS were zest, hope, and gratitude. Further, Wilski and Tasiemski (2016a, 2016b) found cognitive appraisals (i.e. self-efficacy, self-esteem, illness perception) to be more significant for QOL than social support, socio-economic resources and clinical characteristic (e.g. type and duration of MS). Ratajska et al. (2020) point out that lack of social support was associated with depression, anxiety and negative QOL.

### 1.2 | Living with chronic illness and disability

The psychological adaptation for an individual with a chronic illness is best achieved with the greatest possible degree of independence and self-control in their daily lives (Lubkin & Larsen, 2013). Losing independence as a chronically ill person can have serious consequences such as confusion, withdrawal and disorientation (Lubkin & Larsen, 2013). To compensate for this, and conflicts between conflicting emotions and loss of control over their own body, they can seek control over other people and situations, such as controlling every aspect of what will be done to and with them (e.g. resistive behaviour, compliant behaviour) (Lubkin & Larsen, 2013). Charmaz (1983) found that loss of "self" was one of the major forms

of suffering from chronic illness. Patients described in the study of life full of restrictions and social isolation, they felt devalued and felt a burden for others (Charmaz, 1983). This was combined into an experience of having a reduced self-esteem. We know from previous studies that the experience of one's self-image and social image is very important for feeling accepted, recognized and valued (Løkkeberg, 2016; Løkkeberg et al., 2021). This can be put to the test when people become less mobile and become dependent on using a wheelchair to be able to move. Overall, very few studies have been done to find out how people with MS who are in a wheelchair experience quality of life and what is important to them (Devitt et al., 2004; King et al., 2012).

### 1.3 | The purpose of the study

The study includes health-related quality of life for people with multiple sclerosis who live at home and are in a wheelchair. The main focus of this study is to access how people with MS have experienced the transition to being confined to a wheelchair and how the disease has affected their health, identity and quality of life. According to a previous study from Devitt et al. (2004), they found that wheelchair appears to have positive impact on quality of life on self-reports for people with MS. The purpose of our study was to explore how people with multiple sclerosis experienced living with MS and how they perceived their own situation (e.g. threats to QOL). We limited our study sample to wheelchair users living at home to make the group less heterogeneous and to limit the number of potential participants.

## 2 | METHOD

A qualitative design was chosen to be able to produce rich descriptions of people with MSs' experiences of sitting in a wheelchair (Kvale et al., 2015). The participants were recruited through local MS associations in Norway. People with MS who lived in their own homes and who were wheelchair users received information leaflets about the study and were asked to contact research managers if they wanted to participate in the study. Leaders of the local MS associations sent emails to members who met the inclusion criteria. A number of 15 people were asked to participate, and six people agreed to participate in the study. It can be assumed that some potential participants did not want to participate because it would involve talking about topics that some may be perceived as personal and emotional. The included participants had to sign an informed consent that was stored in accordance with current privacy policies. Six participants were included in the study (3 men and 3 women; Average = 54 years, age range: 40–72 years). Participants' reported names were fictitious.

The inclusion criteria were that they had to speak Norwegian, that they had been diagnosed with MS and that they were in a wheelchair when moving and living at home. Participants were asked

to talk about their lived lives and experiences of quality of life. It was challenging to recruit participants as there were few who fit all the inclusion criteria (Table 1).

## 2.1 | The research process

All participants were interviewed in their own homes. During two of the interviews, the spouse was present in the room. We used a voice recorder to record the interviews. The interviews were adapted to the participants' interest, patience and perseverance. The interview guide was semi-structured and provided opportunities for the participants to talk openly about their experiences (Table 2). In meeting with the respondents, we spent time to get to know their situation and toned down our own expertise and experience with the MS disease. The interviews lasted from 60–90 min and were transcribed directly after the conduct. In total, there were 70 pages of transcribed material and were not returned to participants for comments. In five of the interviews, both researchers (i.e. one female, one male) were present, where one was responsible for directing the conversation, while the other observed and noted reflective data (e.g. body language, pauses, emotional mood). In the other two interviews, only one of the researchers was present. During all the interviews, the interview guide was used as a starting point for us to make sure that we came across the same topics.

## 2.2 | Analysis

The transcribed material was analysed with a thematic analysis (Braun & Clarke, 2006), and topics were identified based on the informants' statements. The transcripts were analysed by both authors, and themes were defined into a larger empirical and theoretical context (Braun & Clarke, 2006) (Table 3).

We used NVivo 11 computer software analysis tools to organize transcripts, nodes and themes. We used Braun and Clarke (2006)'s six steps so that we had a systematic approach to the analysis process (Table 4). In step one, we were concerned with getting to know the material and reading through the transcripts several times and highlighting key parts of the text. In step two, we marked the text in all the interviews that we coded to different nodes. These nodes were identified based on words that emerged during the interviews.

Both article authors carried out this coding process individually, and then, we met to discuss the different nodes. In step three, all nodes were sorted and produced under overall preliminary themes. In steps four and five, the goal was to improve the proposed themes and look them up against the defined nodes. All this was presented in thematic mind maps that gave us a visual overview of the process. The themes were reworked several times to be able to be so close in connection with the raw data and the nodes. The model is developed directly from the themes that emerged after the thematic analysis (Figure 1).

## 2.3 | Validity, reliability and reflexivity

According to Tjora (2021), it is central to a valid study that the selection of theory and informants contributes to answering the research questions. The interview guide was designed with open-ended questions and was intended to ensure that the informants were not led to answer in a specific way, but that they were free to present their thoughts and experiences related to overarching topics. According to Kvale et al. (2015), it is important that there is a transparent process that shows that the researchers "analysed findings are related to the informants" statements. This was taken care of with audio recordings and direct transcripts that were reviewed by both article authors. Reliability was ensured by following all the planned steps in the research process in accordance with Tjora (2021). It is very important that the researchers involved in producing the research data have a reflexive approach to this process. According to Willig (2013), personal reflexivity is central to illuminating how the researcher influences research results. Both authors of the article have had MS disease in close relatives and in this way have a lot of prior knowledge about MS and how it affects people. We were aware that this should not govern our questions to the informants and that we did not have a relationship with those interviewed.

## 3 | RESULTS

The results are based on themes that have been analysed in the thematic analysis. Three main themes were identified: Being free and independent, threat to the self and one's identity, and adaptation to MS.

**TABLE 1** Demographics data of patients (i.e. the reported names were not participants' real names)

Participant	Marital status	Diagnose	Age	Gender	Mobility indoors	Mobility outdoors	Years since diagnosis	Work
Susie	Living with spouse	RRMS	60	Female	Wheelchair and walker	Wheelchair	17 years	70%
Nancy	Living with spouse	RRMS	45	Female	Wheelchair and walker	Wheelchair	7 years	Not in work
Aurora	Single	RRMS	43	Female	Wheelchair and walker	Wheelchair	5 years	Not in work
Richard	Living with spouse	RRMS	70	Male	Wheelchair	Wheelchair	40 years	Not in work/Retired
Paul	Single	PPMS	43	Male	Wheelchair	Wheelchair	16 years	Not in work
Gary	Living with spouse	RRMS	72	Male	Wheelchair	Wheelchair	18 years	Not in work

**TABLE 2** The interview guide that was used as a starting point for the MS study

Interview guide
Demographic data
Name:
Age:
Function:
Can you tell us about a typical day for you?
What is life quality for you?
Existential (hope, love, faith, meaning)
Practical (economics, aids)
External framework (NAV, home nursing, GP, hospital)
Psychological perspectives (emotions, worries, coping strategies)
Perceived health (loss of bodily functions)
Network (micro, meso, macro)
Physique (fatigue, sitting in a wheelchair)
General considerations about quality of life and own experience of yourself in the face of MS disease and becoming a wheelchair user
Anything else you want to talk about?

**TABLE 3** Phases of thematic analysis (Braun & Clarke, 2006, p. 87)

Phase and description of the process
1. Familiarizing yourself with your data: Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes: Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes: Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes: Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic "map" of the analysis.
5. Defining and naming themes: Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report: The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

### 3.1 | To be free and independent

This theme is based on the respondents' experience of what was important in everyday life. For many of the informants, quality of life was the same as being free in everyday life. Richard was particularly interested in having a good dialogue with his wife:

When you lose functions, you become a little insecure and lose confidence. It was necessary to have a

dialogue with my wife, and you actually discover that physiological limitations mean that you find other ways of doing things, and practical cooperation. So there are good solutions to that relationship with yourself, is the cornerstone for you to change the relationship with others.

Several of the respondents were clear that it was important to change requirements and life project. Gary was keen to lower the level of ambition:

None of what I did before works now. Except I can use my head. Aids and family teams work well. Had high ambitions, but has had to lower that threshold. Sometimes I am reconciled to it, other times I want to. Then I have to make that settlement. Nothing that says everyone should have the same A4 (regular) life at our age. This is our A4 (regular) life.

Several of the respondents had from childhood been concerned with managing themselves and that this was an important aspect for experiencing quality of life. Paul said, among other things:

Quality of life for me was from when I was quite young. It's the feeling of being able to fend for oneself. To be self-reliant. To avoid asking someone, in quotes bother someone. Be able to do it yourself, its quality of life.

Aurora was particularly concerned about the importance of self-sufficiency. She said the following:

Yes, quality of life is perhaps first and foremost self-sufficient. Moreover, I know that can be challenged eventually, I have known that, and I have had periods where I have been quite close, so I am quite marginal then, in relation to mastering things somehow. So per. today I think that as long as I can manage myself I am very happy about it and really enjoy that opportunity. It is kind of important to me because then you get a freedom on what I know I would not have had. Quality of life in everyday life, getting up and that things in a way go a bit like that in routines, and it gives you a bit like that different perspective on things.

Another respondent was concerned about being seen. Susie said the following:

That I am taken into account. That I know something. So at the same time, one should not forget not only the job, but also the family, one is then, with the family, have a good time and can contribute, help with what I can

**TABLE 4** The analysis process

Raw data – text extracts from transcripts	Nodes	Theme
Quality of life for me it was from when I was quite small it is the feeling of managing oneself. To be self-reliant. I am not; I have people around me and have received help. However, it has been important to me. In addition, that is where illness and disability come in, that is where it appears. Because there are things that can make it difficult to maintain the feeling, you have of being able to manage on your own. Nevertheless, so far, I have been quite lucky, I manage myself.	Manage oneself. Be self-reliant. Have people around me. Things that can be difficult to maintain. The feeling of managing oneself. Pretty lucky and clearer myself.	To be free and independent in everyday life
It is really everything in life whether you have an illness or not. In addition, I have prepared some philosophical considerations that have helped me. That is, I call it relationships. Relationships with yourself, your loved ones and those relationships with those around you. The issue is how to pick out the positive that is in all of us. I believe that all people are born well, but they are disturbed along the course of life. When you lose functions, you become a little insecure and lose confidence. It was necessary to have a dialogue with my wife and you actually discover that physiological limitations mean that you find other ways of doing things and practical housework. So there are good solutions. That relationship with yourself is the cornerstone for you to change the relationship with others. The positive is that for once you have to go into yourself and the environment and maybe puncture some issues and challenges that you never thought of or took for granted	Applies philosophical considerations. Relationships with yourself, to the nearest and to the surroundings. Pick out the positive. All human beings are born well. Loses features that affect self-esteem. Talk to your loved ones about physiological limitations. Learn other ways to do things. Go into yourself. Punctuate issues that you previously took for granted or thought about.	Adaptation to MS

help with, be with our grandchildren, see that we make a difference there. To feel that I have something to contribute to others, to see that others need me.

Nancy was keen to appreciate what one has and said the following:

To have a meaningful life that you are happy with what you have. It will be very different; you get sick in relation to what you had thought. Without being dependent on others and burdening others. This makes it much easier on weekdays.

The informants largely directed the experience of freedom and independence to be closely linked to quality of life. They had several coping strategies that helped them achieve this. Among other things, it was very important to communicate to the environment their limitations and resources and that this helped to give them opportunities for independence. It was also important that they were taken into account and that they were given the same opportunities to be seen and heard in the same way as before they were diagnosed. The cognitive aspects were also central in that they thought that the goals had to be changed and that the requirements had to be reduced in order to experience that they did not lose their experience of independence.

### 3.2 | Threat to the self and one's own identity

This topic addresses the challenges of getting MS and how it affects the respondents' self-worth and identity. Several of the respondents

were concerned that they still had an intrinsic value and could contribute as a resource both in society and in close relationships. But despite the fact that many experienced the wheelchair as a positive factor in being able to participate in daily life, there were also experiences that affected the self and identity in a negative way. Aurora experienced being overlooked when she sat in the wheelchair. She said:

You are somehow overlooked, perhaps difficult for people to meet you in that setting. There are many who do not know where to look.

Furthermore, she pointed out that not being able to work anymore, as a challenge to the identity. She said:

When I suddenly could not seem like a health worker anymore and in a way help others, it was a bit like a trick to get over. That and suddenly sitting there being the one who needed help himself. So the job has been the toughest. For mom, I still am, girlfriend I still am, I kind of have all my other roles, but it was pretty tough. Because it was a big part of me, worked for many years in a place, and in a way have a job that I feel, that I, there has not been a day where I have thought that, I can not bear to go to work somehow, it has been very, the job has been great in all possible ways, so it was very tough, when it no longer worked.

Paul was concerned with distinguishing between what he himself could do something about. He said the following:



**FIGURE 1** Conceptual model of quality of life for people with MS who are in a wheelchair and living at home. The model is developed directly from the themes that emerged after the thematic analysis

Then I hope that I can distinguish between what is beyond my control then, but quite specifically, the fact that I got MS is beyond my control. How I take it is within my control.

He further said:

If some bosses manage to see some productivity in people with disabilities, then I think things could have changed for the better. I have an impression of facilitating in a workplace that they would rather not have. I'm happy to be asked to do something, even though in quotation marks it's more work than just sitting here, but that someone needs me and that I can do something.

Another pointed out mood swings as challenging. Gary said:

I have had many times where I have been depressed, so that comes with it, but have had the ability to get

up again and find new opportunities. Had I not had the aids, I would not have worked at all. Then I could not go to the city once.

Another respondent was concerned that people with MS must take control and gain insight and knowledge. Richard said the following:

The biggest task for a chronically ill person is to have self-insight and know everything about their own illness. We are in a training role.

Susie experienced not being seen as a human being. She said the following:

I see it sometimes when I come to shops or other places; I see that people change their facial expressions when they see that I am in a wheelchair. I knew that before, but I do not care about it. I'm me anyway, and that's it.

Nancy also had several experiences aimed at being overlooked:

It's a downturn when you realise that you can no longer do things yourself and that it gets worse. So when you sit in a wheelchair, not everyone looks at you. They look over you, and then they talk to my husband. Alternatively, ask my daughter. So it does not feel right either. It's almost the worst really. Most people around me realized that I had MS and they realized that I had to start with a wheelchair, but that they suddenly should not talk to me anymore, it was really worse. So that they look over and past you. Just as they fail to accept yourself, fail to relate to it. I have said it very often, that I am the same, and that I understand everything they say. I think it's wrong that they talk to my husband.

The respondents experienced that they themselves were the same people, but that it could be demanding for the environment to see this, and meet them in the same way as before they got MS. When the wheelchair was introduced, it could be a great threat to the experience of themselves and their own identity since they could feel rejected and ignored in the encounter with various public places (e.g. shops, medical centre, concerts).

### 3.3 | Adaptation to MS

The topic shows how many people with MS use several strategies to adapt to the situation and that they largely see it as important mechanisms for experiencing quality of life. Although several of the respondents had reconciled with their diagnosis, it was also important to have a hope for a positive change. Susy was hoping for a cure that could help her:

I hope that there will be a miracle cure. One has to somehow remain hopeful.

Aurora hoped for improvement in her own body and experienced the hope as very important on the days when her form was particularly bad. She said:

Of course a hope. I have a hope, of course I have. Do not give up hoping that your arm will get better. For me, it is with hope that is what I have when I get so bad.

Nancy was also keen to hope:

Then I lie down on the sofa and relax. Then I sit here on the couch and do some MS association stuff. Then I could hope that there was a medicine so that I could be the way I am now. If only something had come to stop it. Then it would have gone well.

Paul also highlighted the hope:

I try to have a realistic hope. Hope is there. That there are medicines that can slow down, not cure, but that I get more alert. So hope is there of course. But not future hope that I will get well, I have no hope for that.

Gary learned that it is important to pay attention to activities because fatigue can come suddenly.

I have had a lot of fatigue in terms of reducing nerve pain and completely lost my basic strength. The fatigue makes me tired and feels that you do not have enough strength, and then you bless.

Richard had adapted to his MS diagnosis and was clear on how he experienced his health. He said the following:

Just as it is, I say to myself, I have no pain and get to sleep at night. Therefore, I could have been much worse. So I would not have replaced gait function with one of the two things. I would not be functional with pain or sleep problems. Therefore, that way, I experience my health as quite ok. Except for the MS then. I would say that there are two important elements in perceived good health.

The respondents were concerned that they were not ill, but that they were in good health. They understood that they had to learn to live with MS, but that at the same time they were conscious of preserving a hope of improvement in the situation. Several also experienced that they had to adapt their lives and activities to the form of the day and especially when symptoms of fatigue became strong.

## 4 | DISCUSSION

The study shows that there are several perspectives that include health-related quality of life for people with MS who live at home and are in a wheelchair. It is important to maintain daily everyday life and experience being a resource for family and friends. It is also important to have a hope and adapt activities to the daily form. Fatigue was pointed out by many informants as demanding to deal with, as it often affected their opportunities to participate in everyday life.

According to the MS Association (2019), not all people with MS have the same symptoms, but our study still shows that there were several compared symptoms that affected the quality of life. In particular, they highlighted fatigue as a problem in order to plan and organize the days as they wished. According to Rousseaux and Pérennou (2004) environment adapting is a key factor and particular when spasticity and pain affect their quality of life. Finding meaning and being able to adapt to the situation is largely about trying to maintain power and living with an unrecognizable body (Olsson



et al., 2008). In our study, we found the informants to try and focus on what they mastered, but at the same time they were aware of their limitations and opportunities in daily life, and that it could affect their quality of life. This can lead to people with MS ending up outside working life and losing opportunities for social relationships (MS Association, 2019).

For many people with MS, quality of life and experience of independence will be greatly affected by where they spend their lives (Riazi et al., 2012). Our informants showed that access to aids (e.g. wheelchairs) could help maintain this independence. Devitt et al. (2004) concluded that wheelchair use has a positive impact on the quality of life for people with MS. In addition to the fact that aids created a sense of security and could help prevent isolation and loneliness (Riazi et al., 2012).

People with MS in our study experienced that much of their identity was changed by the fact that they lost several of their important roles and that they were perceived as less important when they were in a wheelchair. This is consistent with Muzo-Dutton et al. (2012), which referred to an altered "self" that led to mood swings and unstable mental health (Mozo-Dutton et al., 2012). Furthermore, one can assume that losing some of one's identity affects what Maslow (1970) refers to as a basic need and that the experience of feeling less respected and recognized affects the MS affected quality of life in a negative way.

Several of the patients in our study reported that they had a good quality of life and good health. This was related to the fact that they rarely had "common" diseases (e.g. colds) and experienced that the MS disease as something they had reconciled with without affecting the experience of health. In addition, many of our informants had a network of friends and family with whom they had close relationships. This can be seen in connection with what Gabrielsen (2012) describes as important for quality of life that people with MS can be active based on their preconditions and that they experience cohesion and positive emotions. Nevertheless, several informants felt that life had been changed to be routine and isolating. This can therefore also contribute to affecting the quality of life negatively in that everyday life contains less contact with people who are not part of the support system and that there are fewer meaningful activities with less varied and exciting life of experience (Aggernæs, 1988). In a comparable study of people with MS, Thoresen (2000) found that the informants experienced hope as existential and meaningful. They were concerned with maintaining hope even though the situation was very difficult.

Our study also shows that being able to have a hope that there would be a "miracle cure" or that they would not get a worsening of their MS was very central to experiencing quality of life. Hope and meaning in life are connected. The fact that the informants experience meaning can have a positive effect on health (Frankl et al., 2007). It seems that several of the informants used hope as a central part of adapting to life with MS and that this made sense in life. On the other hand, fatigue was something that became a major threat, and in order to cope with the new situation that the disease led to, it was important to have a future-oriented hope that gave

them strength. This is closely related to Frankl et al. (2007) who claim that hope helps to give life meaning and to fulfil a function.

Kübler-Ross and Eckhoff (1973) points out that when the patient with conviction claims that there is nothing more to hope for, death is imminent. This supports the importance that people with MS must be given opportunities to preserve hope when they experience that this helps them to experience more quality of life. According to From (1969), the quality of life deteriorates when hope is threatened, and when meaningful work fails, and the person affected by MS becomes dependent on others, the hope of a dignified life can be reduced. The unpredictability of MS can also contribute to an uncertainty that can be a threat to hope.

#### 4.1 | Strengths and limitations

We found the results credible in that we used the same interview guide with open-ended questions in meetings with all the participants, and we were also concerned not to let our own attitudes about MS affect the participants' answers. We believe it is a strength that the data were analysed and themes identified by both authors, and that we were conscious of setting aside our own appraisals of MS in the interview situation, and that we did not have a relationship with those interviewed. In order to strengthen the findings we could with advantage have included more participants, but we also see that we reached a saturation on the basis as the participants emphasized several of the same perspectives, and there were few new unique themes that emerged from the interviews.

Our results may have been influenced by the fact that it was initially very resourceful informants who participated in this study. We might have had different results if they had had a different social and economic starting point. Future studies should also include participants with different socio-economic backgrounds. We also see that the collection of data took place in a country where the public sector finances health care, in addition to the fact that the health costs of Norwegian citizens are among the highest in Europe (Eide et al., 2020; Statistics Norway, 2018).

## 5 | CONCLUSION

The article has focussed on health-related quality of life for people with multiple sclerosis who live at home and are in a wheelchair. The informants in our study experience that in many contexts, it is demanding to live with a chronic illness. Becoming dependent on others and having a very varied form of day can be difficult. Sitting in a wheelchair was seen as positive in that they could then get around more easily in their own home, or out in the community. At the same time, sitting in a wheelchair also posed a threat to the self and one's own identity in that many people overlooked and approached their spouses. Having good health was pointed out as important, and the informants experienced good health even though they had a serious MS diagnosis.



There were several factors that led to positive consequences, but being able to be an active part of family life and be able to contribute as a resource in one's own family and society had positive consequences of the disease. For further research, it is important that active work is done to find the causes of the disease and which treatment is most effective. Nevertheless, it seems that there is a need for more systematic knowledge about quality of life in connection with patients' experiences and their challenges, as well as what can be helpful when they live in their own home and are in a wheelchair (Riazi et al., 2012).

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## CONFLICT OF INTEREST

There are no conflicts of interest.

## AUTHOR'S CONTRIBUTION

Both authors fulfil the journal's authorship policy and have approved the final manuscript. Both authors have made substantial contributions to conception, design, data collection and analysis of data. First author assumes the main responsibility for the manuscript preparation. All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (<https://www.icmje.org/recommendations/>)]: substantial contributions to conception and design, acquisition of data or analysis and interpretation of data; drafting the article or revising it critically for important intellectual content.

## ETHICAL APPROVAL

The study was approved by REK (Regional Ethics Committee) in Norway and NSD (Norwegian Center for Research Data), reference number 2018/439. Informed consent was given from all participants in the study, and they were told that they could withdraw their consent at any time. The audio files were stored in accordance with the law on the processing of personal data and medical research. All participants were cared for in accordance with research ethics guidelines and in accordance with the Helsinki Declaration.

## DATA AVAILABILITY STATEMENT

Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, apart from what is reported in the article, so supporting data are not available.

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