

Briefing Paper 2

Researching care practices in everyday life with Multiple Sclerosis

Nissen, Nina

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Statuspapir 2

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Livet med Multipel Sclerose

En antropologisk undersøgelse af (egen)omsorg i hverdagslivet med sygdommen.

Forankret hos: REPHA- Videnscenter for rehabilitering og palliation

Finansieret af: Scleroseforeningen

Dette videnskabelige forskningsprojekt vil undersøge, hvilke strategier og aktiviteter, som mennesker med MS og deres nærmeste sætter i værk for at kunne leve et godt liv.

Briefing Paper 2:

Researching care practices in everyday life with Multiple Sclerosis

The study: *Living with Multiple Sclerosis: An anthropological exploration of care practices in everyday life*

The study was conceived of in response to a call from the Danish Multiple Sclerosis Association (Scleroseforeningen) which wishes to actively involve people living with multiple sclerosis (MS) in the research it funds. The study design draws on my long-standing interest and personal involvement in health social movements.

The aim of the study is to explore the ways in which people living with MS and their relatives shape their everyday care practices and their lives in order to live a good life with MS. To this end, an approach to researching the perspectives of people living with MS and their relatives was developed that builds on the call 'Nothing on us without us' demanded by health and disability activists from the 1970s/80s onwards.

The approach which underpins the study comprises three complementary elements:

- A close collaboration with a co-researcher who herself has MS
- The use of qualitative research methods which are often referred to as 'participatory'
- The involvement of a reference group whose members bring a wide range of expertise in the field of MS to the study, including personal, professional, research, rehabilitation and policy expertise.

In this briefing paper, I want to describe these three elements (see Figure 1).

Research team: Data collection, analysis and dissemination

In a very first step of data collection, the research team invited people with MS and their relatives to identify issues they considered of particular relevance to living with MS in contemporary Denmark, and which they thought needed further research. The themes emerging from the focus group discussions (see [Briefing paper 1](#) (in Danish)), together with issues mentioned in the literature on neurodegeneration and MS and the co-researcher's own experience, enabled the research team to gain a broad overview of concerns, areas of significance and topics that may shape care practices and everyday life with MS. Further analysis of this overview, in light of the aims of the study, informed the subsequent in-depth interviews.

Most interviews are one-to-one, a person living with MS interviewed by the co-researcher; on some occasions a person living with MS is interviewed together with a family member, some of whom also have MS. Before each interview the participants are invited to share any photographs of their everyday life,

which they think reflects their lives and care practices and they are happy to share. A participant's photographs are then discussed during the interview, at times providing the starting point for a conversation. This enables the participants to 'bring in' their personal perspective in a particularly active and participatory way and can assist participants to shape an interview in ways they find especially important. This kind of interview tends to be called 'photo-elicitation interview' or simply 'photo-interview'. In addition, one photograph is said to say more than a thousand words. That is, personal photographs tend to contribute different kinds of information to a study (such as emotions and personal reflections) than standard interviews, and help to bring participants' broader perspectives, experiences, practices and concerns to the fore.

The interviews are conducted by the co-researcher, who also shares her own experience of living with MS during the interview, if this is appropriate. Interviews where both the interviewee and the interviewer share a common experience (in this case the experience of living with MS) are often referred to as 'peer-to-peer interview' or 'peer interview', and some researchers say that these interviews are more 'open'.

At the end of each interview, participants are asked whether another researcher could join them in some of their daily activities; that is, activities chosen by the participant. This allows the research team to gain additional insights into what is important to the participants, their everyday lives with MS and their ways of looking after themselves and their health. It also provides opportunities for informal conversations.

Researcher participation and observation in medical settings have also been included. Many people mentioned the importance of their visits to MS out-patient clinics and their rehabilitation stays of 2-4 weeks in one of the MS hospitals. As a result, additional observations are carried out in one out-patient clinic and in one MS hospital.

Throughout the data collection phase, the research team are analysing the data as they go along. In addition, the team has started to disseminate preliminary findings to diverse audiences, and will later write academic articles for publication in international peer-reviewed journals (see Figure 1).

Reference Group: Support, discussion and dissemination

As noted above, the reference group brings diverse and complementary expertise to the study. Overall, one could say that the reference group is in the 'background' of the study, compared to the research team, as also indicated in Figure 1. Nevertheless, the reference group has provided important practical and critical support. For example, individual members helped in recruiting research participants, as well as in setting up visits to an MS out-patient clinic and one of the MS hospitals; the group as a whole has contributed critical comments that helped the research team to think through some initial interpretations, and further similar opportunities to exchange ideas and understandings are planned.

In a next phase of disseminating findings from the research, the reference group will contribute to 'translating' research findings into recommendations for rehabilitation practice, and will also be actively involved in writing an article aimed at health and social care professionals (see Figure 1). In this way, it is hoped that the findings will have a direct impact on services for people with MS and their relatives.

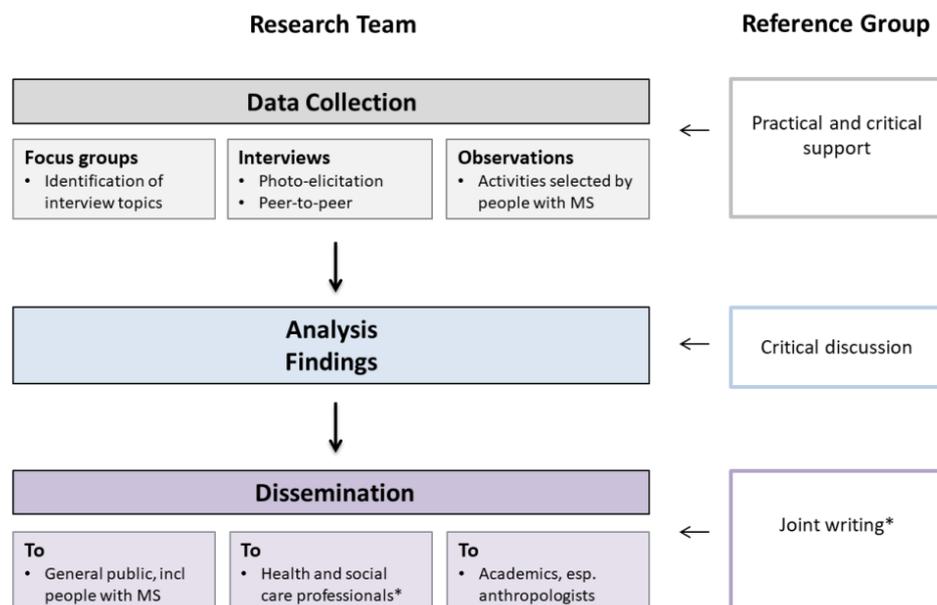


Figure 1: Research approach and process

Concluding remarks

This study aims to foreground the perspectives of people living with MS and their relatives through an innovative research approach that combines participatory research methods with peer-interviewing and the input of a reference group with extensive expertise in the field of MS. As the study is still in progress, it is not yet possible to assess the approach adopted more comprehensively. However, several research participants have positively commented on their experience of participating in the study. For example, some participants found it thought-provoking to contribute personal photographs, others mentioned that being interviewed by a researcher with personal experience and insight into living with MS was a new and good experience, and yet others found it refreshing for a researchers to participate in their activities, such as an exercise class. Early findings indicate that the 'user-involving' approach to researching care practices in everyday life with MS presented here delivers on at least some of the hopes of foregrounding the perspectives and voices of people with MS in diverse and creative ways.

Further information

More information (in Danish) about the project can be found [here](#).

If you have any questions or would like to comment on this briefing paper, please contact Nina Nissen via email nina.nissen@rsyd.dk

Nina Nissen

12 June 2019