

Application of Patient Journey Methodology to Explore Needs for Digital Support

A Multiple Sclerosis Case Study

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Abstract

Multiple sclerosis (MS) is a chronic disease with a highly variable course, and patients face a large number of health professionals during treatment and follow-up. We introduce a methodology for detailed analysis and visualisation of patient journeys. The purpose was to gain insight into MS-patients' needs, experiences, and desires. A case study with three patients over a period of 4-6 weeks revealed how they interact with health professionals in managing their disease. We have identified several areas where digital tools may improve the patients' quality of life, and support health professionals in their follow-up and treatment of MS.

Keywords

Patient journey methodology, multiple sclerosis, patient needs, digital support.

1 INTRODUCTION

Many chronic disease patients experience highly variable disease courses where recurring symptoms or complications can severely affect function level, quality of life and/or relations with their loved ones. Still, they need to manage these day-to-day challenges largely on their own with only intermittent contacts with health professionals.

Multiple sclerosis (MS) is an example of a chronic disease with a very variable disease course. People with diagnosed, stable MS typically consult a neurologist on a yearly basis. These consultations focus primarily on the pathological changes and disease progression, and less on other symptoms and their practical implications. Thus, the patients must handle much of the smaller and larger everyday burdens of the disease on their own.

Digital support tools can be a valuable help for patients who need to navigate a complex and variable disease progression. These tools include eHealth (electronic/web-based health), mHealth (mobile/app-based solutions), and various electronic devices, which can all be active ingredients in order to reduce disease burden, promote self-management, and improve quality of life. However, for such solutions to be helpful, they must be designed based on the patients' needs and experiences and how this varies over time.

The current study therefore aimed to take the patients' perspective and gain insight into their situation and experiences, and how MS affects their lives. A method for mapping of actual patient journeys has been applied to three MS patients over a period of 4-6 weeks. The study also encompasses the health services and the health professionals' needs. Finally, we have identified areas where digital tools may support management, follow-up and treatment of MS patients, and discussed these from the perspective of both patients and health professionals.

2 BACKGROUND

2.1 MS and health service system

Multiple sclerosis is the most common non-traumatic neurological disorder affecting young adults and with high costs for the society [1]. The prevalence of the disease in Norway is 203/100.000 and among the highest world-wide [2]. Disease onset is mainly between 20 and 40 years of age, and women are more often affected than men. In MS the immune system is causing inflammation in the brain and spinal cord leading to lesions and secondary neurodegeneration. Inflammatory episodes are experienced by the patients as episodes of physical or cognitive disability with variable remission. The disease course is highly variable with large inter- and intra-individual variations. The cause of the disease is a combination of a genetic predisposition and most probably environmental factors such as infections, smoking, and lack of vitamin D among other unknown factors [3]. Typical symptoms include gait problems, other motor- and sensory problems, bladder- and bowel problems, fatigue, visual problems, and cognitive issues including reduced attention and memory. Thus, the majority may receive a disability pension of some degree, and many will be in need for practical assistance and different assistive devices. In recent years, several immune modulating treatments have become available aiming at reducing the risk of disease progression, but these treatments are usually most effective early in the disease course, and the long-term efficacy remains to be proven.

Patients with MS will be followed both by the family doctor, specialists in neurology and MS nurses (usually hospital based in Norway). Other specialists needed as well may be physiotherapists, occupational therapists, social workers, psychologists, neuropsychologists, nutritionists, and speech therapists. Many patients will also need short-term stays in rehabilitations units for help with more

complex problems, but most of the time they must manage their life with the disease on their own. As about half of the patients may experience some degree of cognitive problems, the coordination of the support may be a great challenge.

2.2 Existing practices and tools for patient self-management

The use of eHealth and mHealth solutions by persons with MS has been surveyed in a North American cohort in 2017. From 6423 participant responses, it was found that use of IT tools was common in the MS population in order to facilitate health related information, and several (46.2%) also used one or more MS-related apps [4]. A literature review from 2018 reveals an increased availability of new eHealth/mHealth solutions targeted for the MS population [5], and another review gives an account of mHealth apps suitable to support persons with MS [6]. Although the latter study included 30 unique apps, it was found that the apps in general failed to meet patient needs and demands. Still, a literature review revealed that tools for self-management improved quality of life in six out of seven studies, also with some evidence of improvement of depression and anxiety though more robust and further evaluation is needed [7]. In Norway, a self-help program called SPIRIT [8] is offered to support MS patients in managing their disease and the challenges they face. The first experiences in Norway seem positive, but it should be used in a larger extent and then be evaluated.

2.3 Patient pathways and patient journeys

Patient pathways (or clinical pathways, care pathways) have become a key concept when addressing challenges in providing coherent and sustainable healthcare services [9]. Although primarily associated with the clinical dimension, pathways transcend many dimensions like logistics, administration, patient rights, technology, and economy. In this paper we focus on the experience of individuals. For simplicity we use the term *patient journey* to distinguish the actual, individual patient encounters from the planned, normative pathway offered by the healthcare service system.

3 METHOD

3.1 Meetings and observations

We have had several meetings with health service representatives to a) establish an overview of actors and roles involved in diagnosing and follow-up of MS patients, b) reveal challenges and the potential for digital support in a subset of work processes, but also for patient self-management. We have participated in a full-day introductory course for patients at a specialized rehabilitation centre for people with MS, enabling observations and informal conversations with MS patients.

3.2 Mapping of patient pathways and journeys

Service design is an interdisciplinary and practice-based method which originates from the field of service marketing [10] and user-centred development [11]. Service design has a problem-solving approach and originated in the private and public service sector. Lately it has been adopted also in the health sector.

SINTEF has developed a modelling language for service processes and user journeys. The Customer Journey Modelling Language (CJML) can be used both for documentation and analysis purposes and is well suited for describing health service processes and patient journeys [12]. This approach makes a conceptual distinction between the planned, hypothetical journey and the actual journey experienced by a patient. Human experiences are only assigned to real patient journeys, supporting the ISO standard for user experience [13]. A web resource page about CJML and guidelines for use is available at www.sintef.no/cjml.

We conducted an in-depth study of three persons with MS over a period of 4-6 weeks using the method Customer Journey Analysis [14]. First, the target group and the service context are specified. Inclusion criteria were 1) persons who have lived with MS for more than five years and experience challenges, and 2) persons being full time or part time employed.

Patients were recruited through Oslo university hospital. A brief telephone interview was conducted to invite subjects to participate in the study and a physical interview. During the subsequent interview we made inquiries about family situation, work, digital habits, challenges related to MS, need for health services and actors involved, type of treatment and their experiences, and finally needs and suggestions concerning digital tools and support in managing their disease. The three informants were then given a structured diary to fill in. They were instructed to report on every event (contact points, suggestions, thoughts, experiences) relating to MS during the study. After the documentation period, a debriefing interview finalized the data collection with a detailed review of the diary and follow-up questions.

3.3 Ethical perspectives

A description of the planned study and handling of personal data was submitted to the Norwegian Centre for Research Data (NCR) for assessment. The study was found to satisfy the requirements of data protection legislation and was approved by NCR. Participation in the study was voluntary and based on written informed consent. To ensure full anonymity fictitious names have been used throughout, and one or more of the following variables have been manipulated: age, gender, occupation, and family situation. The informants' subjective experiences, however, are reproduced verbatim and authentically, i.e. in their own words.

4 RESULTS

Based on data collection from meetings with key actors in the MS health service we have identified and mapped typical patient pathways for diagnostics and treatment of MS. Next, we have analysed and modelled the actual patient journey of three persons with MS. Finally, we have gained insight in patient needs and derived the potential for digital support. Due to space limitations we only present one patient story and patient journey in section 4.1 to demonstrate the CJA method and the nature of the results. However, data from all the informants are included in the patient's point of view (section 4.2) and the subsequent sections.

4.1 Patient stories and patient journeys

Here we present Sara's situation and her experience with the MS health service. A full description of all the patient journeys can be found in [15].

Sara is 42 years old, married and has three children. She works full time as a medical doctor in a hospital. Sara was diagnosed with MS 15 years ago after experiencing numbness and paralysis in her legs. She sought medical help immediately, and the diagnosis was established in less than a week. It was a tough message to receive as a 27-year-old. Sara was breastfeeding a baby at the time and did not start treatment immediately. The paralysis in the legs gradually subsided by itself, and the disease was calm. After a few years she started with medical treatment in the form of infusions every 4th week at the outpatient clinic. This keeps her mostly free from relapses.

Sara has no visible signs of physical impairment and seems to be very little affected by the disease. Most of her work colleagues and acquaintances do not know she suffers from MS. However, Sara is often completely exhausted after work and experiences periods with fatigue regularly. She is very grateful that her husband takes care of the children's activities after school and during weekends. A few times a year Sara suffers from severe fatigue, making her unable to work for 2-4 weeks. She characterizes herself as a sedate person who enjoys relaxing on the couch with a good book. She thinks that it would have been much more difficult to cope with MS if she had been an active outdoors person.

Digital habits: Sara uses a smartphone, but she is not active in social media. She also uses PC at work and at home. The following health actors are involved in Sara's treatment: the general practitioner (GP, sporadically), the MS outpatient clinic (treatment every 4th week), the neurologist (yearly appointment including MR scans), a physiotherapist (sporadic for guidance with physical exercise). Sara's patient journey is shown in Figure 1, and we follow her through one immunotherapy infusion and the arrangement of the next one. She does not consult neither her GP nor neurologist during the study, thus their corresponding 'swim lanes' are empty.

4.2 From a patient's point of view

The patient journeys analysed were limited in time, but still reveals that the patients are in contact with several health service actors including the GP, a neurologist, a physiotherapist, the pharmacy, labour and welfare services, and human resources department at their employer. One of the informants says: *"You have to be strong to be sick! You must fix everything yourself. Nothing comes automatically."* From the patient's point of view, a single point of contact or a personal contact who can assist with coordination of services would be helpful especially during periods when the disease is demanding. Digital tools enabling users to get an overview of the various

appointments could improve the patient's experience of fragmented services.

Fatigue is common for persons with MS [16-17]. Sara struggles with fatigue regularly. In her opinion, fatigue always comes abruptly without any warning. However, she says: *"My husband complains that I respond too late on early signals of fatigue. But I am not sure these signals exist!"* More knowledge of what causes and possibly reduces the experience of fatigue would be important for MS patients to handle work and everyday life. Furthermore, identification of early signs of an upcoming period of fatigue would be important. If such knowledge exists, simple tools could be developed to help predict periods of fatigue, and thus possibly reduce the effects of fatigue or at least prepare for it. This would be helpful as 40% of persons with MS experience fatigue as the major problem of the disease [16].

Another patient mentions the challenge of handling depressions and periods of discouragement. She says, *"You do not call your neurologist when having a depression!"* She would like to have a low-threshold service enabling her to ask for help in coping with the mental side of the disease. *"I do not participate in courses about MS – it becomes too much focus on wheelchairs and hospital"* says another patient. They point out that they miss courses for persons who are mildly affected by MS. The neurologists point out the existing possibilities for mildly affected patients: there are different courses available and also relevant rehabilitation options. The national MS society facilitates networks and arrangements for various patient groups. These are important arenas for information and guidance, in addition to establishing informal groups and relations between persons sharing the same challenges. The health care professionals further point out that the patients are not necessarily aware of the options available in MS care, such as the actual content in courses for newly diagnosed or updated rehabilitation courses for mildly affected patients. Nevertheless, these mentioned possibilities are scarce and most often with waiting lists.

Another area mentioned is physical activity and exercise, which the patients in the study experience to be positive for their disease but must be adapted in periods with relapses and/or fatigue. Knowledge is growing on how exercise and activity affect quality of life in general, and how it affects symptoms and fatigue in particular. Some patients mention that they do not want exercise groups targeting persons with MS, although they would like to get in touch with peers facing the same challenges.

These experiences address MS patients' wish to manage their everyday and professional life and to reduce the burden of their disease.

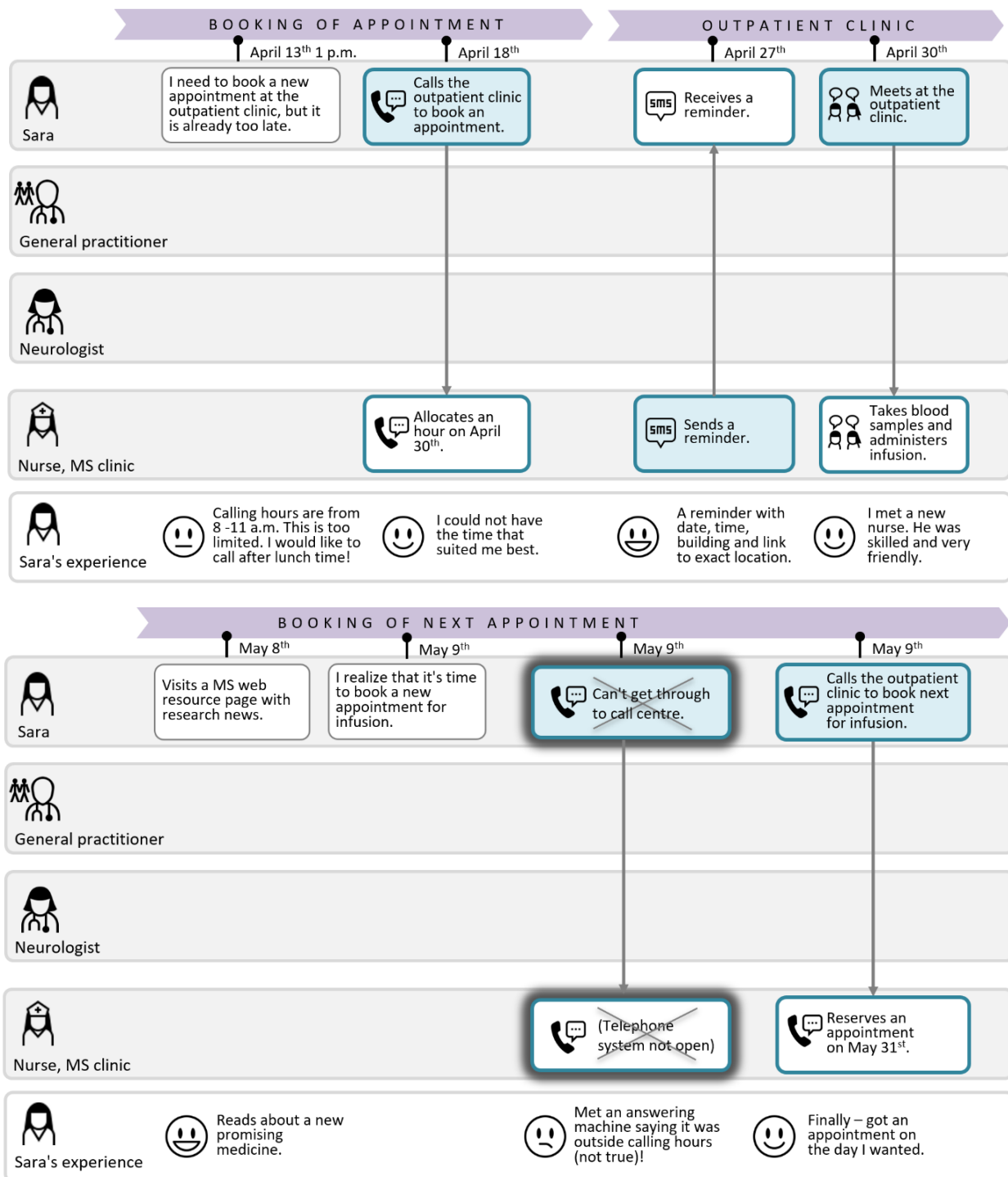


Figure 1 Sara's patient journey.

4.3 The health service and digital support

The study has mainly focused on the patients, their journeys and related experiences. Through the patient journey methodology, we have established insight into their needs and the potential for digital support. Further insight is achieved through meetings with health professionals and observations at a MS rehabilitation centre.

In the following areas, digital solutions can be developed and utilised to support MS patients and the healthcare professionals:

- Communication, interaction and cooperation between various health service actors and patients.

- Patient diaries for documenting treatment and patient experiences throughout their (fragmented) journey, for their own interest and to share with their therapists.
- Documentation of a) planned journeys to support a common understanding across various health service actors, and b) communicating examples of actual journeys experienced by patients.
- Facilitate the start and the end of a rehabilitation period – and related evaluation.
- Follow-up in collaboration with the patient and other prime stakeholders relevant in the patient journey.

Next, digital solutions can be utilised to get further insight in the following areas:

- Monitoring and follow-up of patients with symptom registration, to study impact of exercise and activity.
- Impact assessment of different follow-up and treatment schemes, including rehabilitation periods. Motivate and engage patients to follow up interventions and activity in a tailored manner.

5 DISCUSSION

While patients often find the medical treatment satisfactory, several studies indicate that the coordination among health actors are poor [18,19,20]. For MS patients, the family doctor does not know what the neurologist has done until the report is available and the opposite. There is no (or scarce) formal communication between the doctors and the other therapists, and the patient will often have the role as "the messenger" and "the service integrator" [21]. Thus, the patients wish for real-time communication systems between the different health care providers, and for the ability to themselves follow the communication and be updated. In addition, easy access to the different health care providers through a secure digital solution is a wish from the patients.

Digital support for the follow-up of medications, mental and physical training, and other rehabilitation interventions, may also be useful for the patients. Digital solutions for self-management for persons having MS may be helpful and improve quality of life. The study identifies a need for digital solutions to promote exercise, activity or other behavioural changes over time and to evaluate the effect/impact of exercise, activity, and other interventions. This can also be used to support their mental health. Next, the patients addressed the need for a diary to keep notes related to their treatments and their own experiences through their journey. Such a diary can also provide therapists with more information on the development of the disease and symptoms. The opportunity of digital support for appointments to remind the user and potentially for cooperation between various actors and to follow-up medication, was also highlighted.

This paper demonstrates a methodology to elicit insight into patients' challenges and a visual format for patient journeys using a modelling language. Comparing the three patients included in this study showed several shared challenges. The neurologists, as representatives of specialized health care professionals, found it particularly useful to gain insight in the patients' detailed experiences with the health service, which are typically not elicited through the regular, medical consultations.

The study has been conducted with a limited number of informants and for a restricted period of time, and the results are thus not representative neither for the health services in general, nor for MS patients in general. MS is a disease with highly variable disease course, thus a greater number of informants is needed to cover all aspects of the disease. However, the study has described a methodology that was suitable to reveal detailed patient journeys, and how individuals manage and experience a chronic disease, their needs and desires.

6 FUTURE WORK

Our premise is that digital tools may support persons with MS and the health actors involved in their treatment and follow-up. We suggest further investigations into the following areas:

- Establishment of a larger set of actual patient journeys across age groups and health regions to achieve more conclusive data on needs and preferences.
- Further development of the methodology to incorporate experiences from other informants, e.g. next-of-kin, supplementing the actual journeys with highly relevant and valuable perspectives.
- Digital support for structured diaries that incorporates perspectives and experiences from involved health professionals.
- Knowledge on how symptoms, for example fatigue, be measured, managed and possibly reduced.
- Digital support for increased physical exercise with inclusion of a "digital coach", and how it may affect fatigue and quality of life.
- Digital support for managing, and possibly prevention of, psychological challenges.
- Digital solutions to integrate and structure the scattered communication among all the health professionals and healthcare organizations involved in treatment of MS.

7 ACKNOWLEDGEMENT

This work was partially funded by the Norwegian Directorate of Health through the InnoMed program for innovation in the health and care sector in Norway. We want to thank our informants for their effort and valuable feedback.

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