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Faculteit Geneeskunde en Levenswetenschappen

master in systeem- en procesinnovatie in de gezondheidszorg

Masterthesis

The Experiences and Perceptions of People with MS Regarding Prognostic Information and Tools

Helena Smeers

Scriptie ingediend tot het behalen van de graad van master in systeem- en procesinnovatie in de gezondheidszorg

PROMOTOR :

Prof. dr. ir. Liesbet PEETERS

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Preface

With great pride, I present this master's thesis, which explores the experiences and perceptions of People with Multiple Sclerosis (PwMS) regarding prognostic information and tools. This research, conducted as part of my master's program in System and Process Innovation in Healthcare at UHasselt, utilized a mixed-methods approach to gain a deeper understanding of how PwMS experience the communication of prognosis, their informational needs, and their emotional responses to receiving prognostic information.

This journey began with a clear interest in improving the patient-provider relationship in MS care, particularly in the context of prognosis communication. The complexity of the topic soon became obvious, as the exchange of prognostic information is a highly sensitive and nuanced process. Using a qualitative method (focus groups) and a quantitative method (a survey), this research aimed to provide insights into the needs, challenges, and preferences of PwMS regarding prognosis discussions and the use of prognostic tools.

Throughout this research, I was fortunate to receive invaluable guidance and support from several key individuals. I would like to express my sincere gratitude to my supervisor, Dr. Ir. Liesbet Peeters, for her ongoing support and expert guidance throughout the research process. I am also deeply grateful to Dr. Sofie Aerts, who served as my daily supervisor, providing essential direction and insight into the research. Additionally, I would like to thank Dr. Ir. Ilse Vermeulen, who moderated the focus groups and provided valuable feedback throughout the data collection process. Finally, my sincere thanks go to Dr. Deborah Severijns, who acted as a third analyst, ensuring the rigor and clinical relevance of the analysis.

While the thesis was written independently, their contributions were essential to shaping the direction and quality of this research. I am deeply grateful to the participants who shared their personal stories. Their openness lies at the heart of this study and offered essential insights into what it's like to live with MS.

This master's thesis represents the culmination of hard work, dedication, and learning. I hope the findings presented here will contribute to a better understanding of the role of prognostic communication in MS care, ultimately helping to improve the quality of life for PwMS through more informed, empathetic, and personalised care.

Abstract

This study evaluates the experiences of People with Multiple Sclerosis (PwMS) regarding prognostic information and tools, aiming to understand how prognosis is communicated and perceived. Given the complex and unpredictable nature of MS, effective communication of prognosis is essential for guiding PwMS in managing their condition. A mixed-methods approach, combining qualitative focus groups and quantitative surveys, was employed to analyse the informational needs, emotional responses, and preferences of PwMS in relation to prognosis discussions and the use of prognostic tools.

The findings indicate a significant impact of clear and personalised communication in enhancing PwMS' understanding of their condition and potential disease progression. Participants reported feeling more confident and informed when prognostic information was communicated empathetically and tailored to their individual needs. Moreover, the use of prognostic tools, when integrated into shared decision-making, was seen as valuable in fostering a sense of control and reducing anxiety about the future.

This research provides important insights into how prognosis is communicated in MS care and highlights the need for a more individualised approach in both information delivery and decision-making. These findings contribute to improving the quality of care and the overall well-being of PwMS, offering a foundation for future enhancements in the practice of MS prognosis communication.

Introduction

Multiple sclerosis (MS) is a chronic autoimmune disease that affects the central nervous system. It results in nerve damage through demyelination, inflammation, and neurodegeneration, which manifests in a range of neurological symptoms such as motor dysfunction, sensory impairments, and cognitive challenges. It is the disease's heterogeneous nature that makes predicting the course of MS so challenging (1,2). This unpredictability, along with the view of MS as a continuum, makes prognosis even more difficult (3,4). Traditionally, MS has been classified into subtypes such as Relapsing-Remitting MS (RRMS) and Secondary Progressive MS (SPMS) (5). However, research now suggests that disease progression may occur subclinically from the onset, as seen in concepts like "smouldering MS" and "Progression Independent of Relapses" (PIRA)(6,7). These developments emphasise the need for more innovative tools to improve prognostication (8).

Despite advances in Disease-Modifying Therapies (DMTs), selecting the proper treatment remains complex (2,9). Neurologists face the challenge of selecting the most appropriate therapy during the early disease stages, when the window for effective intervention is limited (10,11). Prognostic tools that integrate prognostic factors such as biomarkers, genetic data, and clinical history could help guide these decisions, providing a more personalised approach to MS care (12).

The use of predictive instruments, including the OLAP (Online Analytical Processing) model, is increasingly prevalent in projecting disease progression in people with MS (PwMS) (13). Kosch (2021) highlights the value of such tools in generating more detailed and personalised prognostic models, which may help reduce uncertainty and enhance patients' understanding of their future (13). Despite the growing availability of prognostic tools, little is known about how PwMS perceive and use them in clinical practice (14). Research indicates that many patients lack access to proactive prognostic discussions with their neurologists, contributing to frustration and unmet informational needs (14). While some PwMS value these conversations, others find them emotionally distressing or feel they fail to address practical concerns (14).

Given the variability of MS across physical, emotional, and cognitive domains, and its unpredictable course, personalised communication is crucial (14–16). Many PwMS report feeling unprepared for the future, particularly when prognostic discussions are insufficiently tailored to their individual concerns (17). Understanding patients' perspectives is essential to ensure that prognostic communication aligns with both emotional and informational needs. To address these gaps, a more nuanced and individualised approach to prognostic counselling is required, one that acknowledges the diversity of patient experiences and balances the benefits of prognostic clarity with sensitivity to emotional impact (15,18,19).

This study explores the experiences of PwMS with prognostic communication, focusing on their informational needs, preferences, and the emotional impact of receiving prognostic information. It examines how PwMS perceive and process this information, whether their informational needs are met, and the emotional and practical implications of prognosis discussions. Additionally, this research explores the nature of these discussions with neurologists, identifying barriers and facilitators to effective communication. The study also assesses the role of prognostic tools in shared decision-making and personalised care planning, with the aim of improving the alignment between prognostic communication strategies and the needs of PwMS. By incorporating patients' perspectives into the development of prognostic tools, this research seeks to enhance the delivery of prognostic information, optimize patient-clinician interactions, and foster a more patient-centred approach to MS care.

Methods

Research Design

This study employed a mixed-methods approach combining qualitative and quantitative research methods to explore the perspectives of PwMS on prognostic tools. The qualitative component, consisting of focus groups, aimed to provide in-depth insights into patient experiences, while the quantitative surveys captured broader trends and preferences. The qualitative component was given more weight, as the primary objective was to explore patients' perspectives in detail. A phenomenological framework was applied to gain in-depth insights into patients' experiences, expectations, and concerns regarding prognostic information. The study followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) to ensure methodological rigor and transparency (20). A completed COREQ checklist is provided in the supplementary materials.

Study Setting and Participants

Participants were recruited from Noorderhart, the Rehabilitation and MS Center in Pelt, Belgium, and online platforms. A diverse sample of PwMS was selected, ensuring representation across age, sex, disease duration, and MS subtype. Inclusion criteria were a confirmed MS diagnosis, age 18 or older, and the ability to consent and participate in Dutch-language focus groups.

Table 1 presents an overview of the demographic and employment characteristics of 16 study participants. Continuous variables are reported as median (IQR) and categorical variables as counts and percentages. The median age was 47 years (IQR: 36-54), indicating a middle-aged cohort. The sample was predominantly female (81.2%), with 18.8% male participants, most receiving treatment for multiple sclerosis (MS) primarily in Limburg, with a few from other regions of Belgium.

In terms of MS subtypes, 18.8% (n=3) had an unknown subtype, while 50.0% (n=8) had Relapsing-Remitting MS (RRMS), 18.8% (n=3) had Secondary Progressive MS (SPMS), and 12.5% (n=2) had Primary Progressive MS (PPMS). This diversity in subtypes reflects the variability in disease progression and symptomology within the MS population. Disability, assessed by the Expanded Disability Status Scale (EDSS), varied: 37.5% (n=6) had scores between 0 and 5, indicating mild to moderate disability, while 6.3% (n=1) had scores between 6 and 10, reflecting moderate to severe disability, and 56.2% (n=9) had unknown scores.

Regarding education, 18.8% (n=3) had only secondary education, 50.0% (n=10) held MBO/HBO/bachelor's degrees, and 45.5% (n=10) had master's degrees or higher. Employment status revealed diversity: 18.8% (n=3) were employed full-time, 31.2% (n=5) part-time, 6.3% (n=1) held both positions, 12.5% (n=2) were retired, and 31.2% (n=5) were unable to work.

Table 1: Demographic and work-related characteristics of participants (n = 16)

Variables		Total n = 16
Age		
	Median(IQR)	47 (36-54)
Sex		
Male	n(%)	3 (18.8)
Female	n(%)	13 (81.2)
Province treatment centre		
Limburg	n(%)	13 (81.2)
Antwerp	n(%)	1 (6.3)
Flemish Brabant	n(%)	1 (6.3)
West Flanders	n(%)	1 (6.3)
MS Subtype		
Unknown	n(%)	3 (18.8)
RRMS	n(%)	8 (50.0)
SPMS	n(%)	3 (18.8)
PPMS	n(%)	2 (12.5)
EDSS Score		
Unknown	n(%)	9 (56.2)
EDSS 0-5	n(%)	6 (37.5)
EDSS 6-10	n(%)	1 (6.3)
Educational level		
Secondary education	n(%)	3 (18.8)
MBO/HBO/Bachelor	n(%)	8 (50.0)
Master or higher	n(%)	5 (31.2)
Employment status		
Full-time	n(%)	3 (18.8)
Part-time	n(%)	5 (31.2)
Full-time & part-time	n(%)	1 (6.3)
Retired	n(%)	2 (12.5)
Unable to work	n(%)	5 (31.2)

Note. RRMS = Relapsing-Remitting Multiple Sclerosis; SPMS = Secondary Progressive Multiple Sclerosis; PPMS = Primary Progressive Multiple Sclerosis; EDSS = Expanded Disability Status Scale; MBO = Secondary vocational education; HBO = Higher vocational education.

Data Collection

Data were collected between January 2025 and February 2025 using semi-structured focus groups and structured surveys. Two focus groups were conducted at Noorderhart, Rehabilitation and MS Center in Pelt, Belgium, with five and four participants, respectively, and one at Hasselt University in Diepenbeek, Belgium, with seven participants. The focus groups were in-person to facilitate direct interaction and open discussion. The exact average duration of the three focus groups was 72 minutes.

The focus group guide and survey, which can be found in the supplementary materials, covered the following key topics:

1. Gaining insight into how people with MS experience receiving prognostic information, identifying their specific needs, and its impact.
2. Understanding how prognosis discussions with neurologists unfold and exploring ways to improve these conversations.
3. Exploring the role of digital tools in assessing prognosis and supporting prognosis discussions.

The focus groups were moderated by a researcher who, while familiar with qualitative research methods, is still gaining experience in qualitative health research. To minimise potential bias linked to this relative inexperience, the researcher followed standard procedures and aimed to remain objective throughout the sessions. Importantly, the moderator had no prior relationship with any participant, supporting impartial discussions.

Each session was audio-recorded with the informed consent of the participants. The focus groups were conducted in Dutch. All quotations were translated into English. This translation was carried out carefully to preserve the original meaning and context of participants' responses. However, it is important to note that the transcriptions were non-verbatim. While the core content of the discussions was captured, non-verbal cues and extraneous elements such as filler words were omitted, focusing instead on the key themes and expressions that emerged from the conversations. For analysis, two independent analysts will code the transcriptions, with a third analyst to enhance the reliability and validity of the process. This collaborative approach ensures an unbiased and consistent analysis of the data.

Additionally, structured surveys were administered to all participants following the focus groups. The surveys were designed to assess several key areas, specifically: participants' clinical data, their experience with prognostic information, the need for further prognostic information, the impact of prognostic information, and their trust in and use of prognostic tools. These areas were explored through structured questions that allowed for the capture of both quantitative trends and qualitative insights. The survey can be found in the supplementary materials.

Data Analysis

This study primarily employed a qualitative approach, with quantitative data collected as a secondary component to provide contextual insights. Qualitative data were analysed using thematic analysis, following a structured data analysis process as visualised in Figure 1. After conducting three focus groups with PwMS, the transcripts were produced and reviewed by Analyst 1 for familiarisation. Open coding was carried out by Analyst 1, followed by consensus coding with Analysts 2 and 3 to ensure consistency. Based on this, Analyst 1 developed a codebook and grouped the codes into subthemes, which were refined through team discussions. Finally, overarching themes were constructed and finalised through consensus among all three analysts.

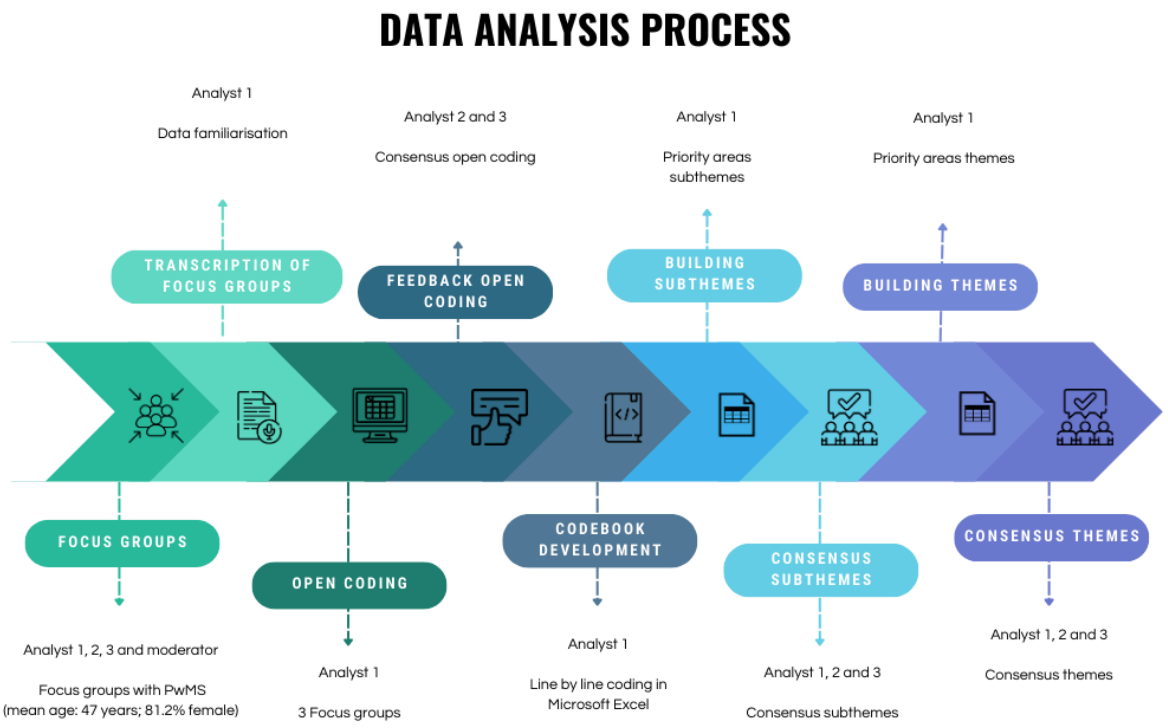

Figure 1: Data analysis process

Thematic analysis was chosen for its flexibility to reveal key patients' experiences and unexpected insights. Analyst 1, a Master's student at UHasselt in System and Process Innovation in Healthcare at UHasselt, was responsible for transcribing the sessions and contributed to the thematic analysis. Analyst 2, a PhD student at UHasselt in Clinical Biomedical Sciences, collaborated in the analysis process, bringing her expertise in clinical research. Analyst 3, Research Coordinator at Noorderhart (Rehabilitation and MS), acted as a third analyst, ensuring the clinical relevance of the analysis.

The analysis began with open coding to identify key concepts, conducted mainly by two analysts who refined the codebook to incorporate emerging themes. A third analyst ensured consistency, and data saturation was reached when no new themes emerged from focus groups, ensuring comprehensive participants' perspectives. Regular discussions among analysts maintained reflexivity to mitigate biases. Microsoft Excel facilitated systematic data management and coding, supporting a structured and systematic approach to identifying and analysing themes and subthemes within the dataset.

The codebook was refined step by step, based on participants' experiences, allowing themes to emerge naturally. Themes were checked against the transcripts to ensure they stayed true to what participants shared. Regular team reflections helped reduce bias and question assumptions during the analysis.

To ensure the trustworthiness of the findings, several quality assurance strategies were employed, in line with recommendations from Holloway and Galvin (2017). These included methodological triangulation to enhance the credibility of the analysis by incorporating multiple perspectives throughout the coding and interpretation process (21). Peer debriefing was conducted by discussing the analysis with colleagues (analyst 2 and 3), providing an external perspective to identify any interpretative biases (21).

Quantitative data (surveys) were analysed using Microsoft Excel. Descriptive statistics were calculated to summarise and study key variables, including frequencies and percentages. Graphical visualisation, such as a table, was used to depict trends in the data, offering a visual interpretation of variations across different MS subtypes and levels of experience with prognostic discussions.

Ethics statement

The study received ethical approval from the Ethics Committees of Noorderhart and Hasselt University (CME2024/058). All participants provided written informed consent before participation. They were informed of their right to withdraw at any time without consequences. Audio recordings were permanently deleted after transcription. Any identifying information was removed before data analysis and publication to protect participant privacy.

Results

Five Main Themes Identified: From Trust in the Care Relationship to Self-Determination and Control

Following thematic analysis, several key themes emerged that reflect how PwMS perceive and cope with prognostic information. These themes include their understanding of prognosis, emotional and practical responses, communication experiences with neurologists, and trust in prognostic tools. Illustrative quotes (Q1–Q11) are presented in Table 2 to highlight the perspectives and experiences of the participants.

Table 2: Summary of Themes with Illustrative Participant Quotes, Referenced by Focus Group and Participant Identification Numbers

Theme	FG/ ID	Quotation
Theme 1: Trust and Distrust in the Care Relationship	FG3/ ID15	**Q1:** "But it was never really about prognosis, only when I asked myself."
	FG3/ ID11	**Q2:** "Yes, but also, it's only fifty percent. Glass is half full here."
	FG3/ ID12	**Q3:** "Yes, I was told that a lot in the beginning, too, he said." "If you say I can't concentrate. I forget a lot. But yes. You're fifty. Yes, everyone forgets more by then. So, that got heard a lot."
Theme 2: Living with Uncertainty and the Longing for Anchors	FG3/ ID16	**Q4:** "So then you just think of, I was 38 at the time. It's the same thing waiting for me." ... "But I had decided on, I'm not going to tell that to him. And certainly not those things."
	FG2/ ID7	**Q5:** "We came out and we spoke. So after 10 years of MS, that's actually the first time we've had a decent explanation."
Theme 3: The Right Information at the Right Time	FG1/ ID2	**Q6:** "Yes, I asked for it myself, of course."
	FG3/ ID14	**Q7:** "Because like I said, everyone is different."
Theme 4: The Pitfalls of Prognostic Overreliance	FG2/ ID9	**Q8:** "That was already, but afterwards there was just a conversation, then look, those are the types of MS and that with that, but we're not going to be able to say now in which group that you belong to and that's never come up again."
	FG1/ ID3	**Q9:** "And I think certainly with something like that, there can be a real need. If you've been told that you want to check with a normal person, I'm going to call it that, without being negative or positive, just with somebody else."
Theme 5: Self-Determination and Sense of Control	FG2/ ID6	**Q10:** "When you make a choice, you come to a crossroads, shall I do that now, shall I not do that now? Then I'm always like, I'm going to do that, then I just can't have any regrets afterwards."
	FG2/ ID7	**Q11:** "Yes, I am also not an anxious person, so I take what comes. And I try to put off as much as I can, but I've never been anxious."

NOTE. FG 1 = Focus group 1; FG 2 = Focus group 2; FG 3= Focus group 3; ID = Identification Number.

Theme 1: Trust and Distrust in the Care Relationship

Trust between PwMS and healthcare providers is crucial for effective prognosis communication. When trust is present, patients are more likely to engage with and process prognosis information, even in uncertainty. Conversely, distrust leads to disengagement and emotional withdrawal, as patients feel their informational and emotional needs are unmet.

A key issue was asymmetrical communication. Many participants reported having to actively seek prognostic information, rather than receiving it proactively from their healthcare providers. This left patients feeling disempowered and uncertain about their future. As one participant shared: "But it was never really about prognosis, only when I asked myself" (Q1). This reflects the lack of initiative from providers and the emotional disconnection that results in frustration and detachment. Such asymmetry reinforces the need for proactive communication from healthcare providers.

When trust existed, patients felt more comfortable engaging in prognosis discussions. Trust acted as a facilitator, allowing patients to actively participate in processing their prognosis. One participant expressed: "Yes, but also, it's only fifty percent. Glass is half full here" (Q2). This quotation illustrates cautious optimism, where trust in the healthcare provider enables patients to cope with uncertainty more resiliently. It not only supports the delivery of prognostic information but also promotes emotional balance, helping patients engage more positively with difficult conversations.

Emotional resilience supported by trust was a recurring theme, enabling participants to engage with difficult prognostic information in a constructive manner. One participant shared: Yes, I was told that a lot in the beginning, too," he said. "If you say I can't concentrate. I forget a lot. But yes. You're fifty. Yes, everyone forgets more by then. So, that got heard a lot" (Q3). This complex remark shows acknowledgment of uncertainty while downplaying emotional distress by relating cognitive challenges to age. This form of coping highlights how trust allows patients to reframe difficult conversations, making them more manageable and enabling them to navigate uncertainty without feeling overwhelmed.

Theme 2: Living with Uncertainty and the Longing for Anchors

For many patients, the uncertainty of living with MS created ongoing anxiety and emotional vulnerability. Prognostic information was valued not only for its factual content but also for its potential to offer psychological stability. Clear and timely communication was seen as essential for managing the emotional impact of this uncertainty.

Patients often sought clear and predictable information about their future, as it helped them feel more in control of their unpredictable condition. One participant expressed: "So then you just think of, I was 38 at the time. It's the same thing waiting for me." ... "But I had decided on, I'm not going to tell that to him. And certainly not those things" (Q4). This quotation illustrates how prognostic information served as an emotional anchor, offering stability, supporting future planning, and providing psychological relief. Understanding one's prognosis helped patients feel more empowered in managing their condition.

However, receiving prognostic information was not always a straightforward process. For some participants, the information triggered feelings of fear and anxiety about what the future might hold. FG2/ID7 noted: "We came out and we spoke. So after 10 years of MS, that's actually the first time we've had a decent explanation" (Q5). This highlights that while clarity and certainty are desired, the emotional impact of the information can also be significant, requiring careful consideration of how and when it is shared with patients. Many participants emphasised the importance of not just clear but also empathetic communication when sharing prognosis information. They wanted healthcare providers to acknowledge the emotional weight of receiving such information. This approach would provide patients with the psychological support they need, fostering a sense of collaboration and understanding during difficult conversations. Clear

communication without empathy can result in patients feeling overwhelmed and unsupported, which underscores the importance of emotionally intelligent care when discussing prognosis.

Theme 3: The Right Information at the Right Time

The timing of when prognosis information is shared is a crucial element in how it is received and processed by patients. This mismatch often led to heightened feelings of stress and confusion. Several participants described feeling overwhelmed when receiving information, either too early in their diagnosis or too late, when they were already emotionally vulnerable.

One of the most frequent concerns was the lack of proactive communication from healthcare providers. Many participants indicated that they had to actively request prognosis information, rather than receiving it at the appropriate time. FG1/ID2 explained: "Yes, I asked for it myself, of course" (Q6). This suggests that healthcare providers were not fully engaged in proactively sharing critical information. This delay in communication added to the emotional burden faced by patients, leaving them feeling as though they were being left in the dark about important aspects of MS.

Participants also noted that their emotional readiness to receive prognosis information varied greatly. One participant shared: "Because like I said, everyone is different." (Q7). This variability in readiness highlights the importance of personalised care, where healthcare providers assess a patient's emotional state and readiness to process complex prognosis details before disclosing them. A more individualised approach to timing would help ensure that patients are prepared to receive and internalise the information.

Theme 4: The Pitfalls of Prognostic Overreliance

Prognostic tools for predicting MS progression have gained popularity in recent years. While they offer valuable insights, overreliance may lead patients to overlook the individual complexity of their condition. This highlights the need for personalised interpretation by healthcare providers.

Participants expressed concern about relying on these tools without addressing the individual patient's situation. One participant reflected on a discussion with a healthcare provider that highlighted MS classifications but offered no specific guidance: "That was already, but afterwards there was just a conversation, then look, those are the types of MS and that with that, but we're not going to be able to say now in which group that you belong to and that's never come up again" (Q8). This quotation illustrates the uncertainty and frustration patients feel when providers offer general MS classifications without clarifying where the patient fits specifically. Different types of MS are acknowledged, the absence of follow-up leaves patients without clear guidance or closure. This lack of personalised information fosters feelings of vulnerability and a sense of being unsupported in understanding their disease progression.

In contrast, the role of healthcare providers is vital in interpreting not only the data from prognostic tools but also in providing personalised care and emotional support. Healthcare providers can help patients understand the limitations of prognostic tools and how these tools fit into their overall care plan. One participant expressed the need for validation and clarification from another professional, demonstrating the need for further support: "And I think certainly with something like that, there can be a real need. If you've been told that you want to check with a normal person, I'm going to call it that, without being negative or positive, just with somebody else" (Q9). This illustrates the vulnerability that can arise from uncertain predictions and the importance of clear communication to ensure patients don't feel overwhelmed or misled.

Theme 5: Self-Determination and Sense of Control

A central theme emerging from the focus groups was the desire for self-determination and control in managing MS. Participants wanted to feel empowered to make decisions about their care, especially regarding treatment options and understanding their prognosis. The ability to maintain control over their health was viewed as a crucial aspect of psychological well-being.

Many participants emphasized the importance of autonomy in decision-making. One shared: “When you make a choice, you come to a crossroads, shall I do that now, shall I not do that now? Then I'm always like, I'm going to do that, then I just can't have any regrets afterwards” (Q10). This statement highlights the need for clear and transparent information, enabling patients to make choices aligned with their values and goals.

Despite the uncertainty inherent in MS, participants expressed a strong desire to manage the unpredictability of their condition by retaining control over aspects of their care. One participant shared: “Yes, I am also not an anxious person, so I take what comes. And I try to put off as much as I can, but I've never been anxious” (Q11). This reflects the emotional resilience of patients striving to maintain agency amid ongoing uncertainty. Autonomy in care decisions helps them feel empowered and better able to cope with their condition’s unpredictability.

Autonomy in healthcare is not only about decision-making. It is also about the psychological benefits of having control over one’s disease journey. PwMS, who face ongoing uncertainty, want to have some degree of predictability and agency in how they navigate their disease. The ability to make informed decisions gives them a sense of control, which is crucial for maintaining psychological well-being in the face of an unpredictable condition.

Patient Experiences, Needs, and Trust in Prognostic Tools: Survey-Based Insights

To complement the qualitative findings, a quantitative analysis was conducted to explore how PwMS engage with prognostic tools. These findings provide additional insight into the diversity of patient experiences and expectations surrounding prognostic communication. The full set of survey questions and corresponding response distributions on patient preferences, concerns, trust, and use of prognostic tools among PwMS is presented in supplementary materials.

Most participants expressed a strong need for more information about their prognosis. Eight wanted a bit more detail, while four desired significantly more, with none feeling adequately informed and four participants wanting to avoid such information. The main areas of interest included the impact on daily life (n=6), likelihood of cognitive decline (n=8), and potential progression to secondary progressive MS (n=7). Concerns about the disease course were common. Twelve participants felt somewhat worried, and three experienced considerable anxiety. Interestingly, while nine believed increased prognostic information would be reassuring, six thought it might heighten their anxiety.

In 12 of the 16 cases, prognosis had been discussed with a neurologist, often initiated by both parties. Eight participants found these discussions (very) useful, though three reported inconsistent prognostic messages from different healthcare providers, highlighting the need for better communication.

Trust in prognostic tools was moderate: nine participants felt average confidence, four had high confidence, and three had little trust. Most participants preferred their neurologist over prognostic tools, although there was openness to using such tools alongside professional guidance. Ten stated they would only use these tools in consultation with a healthcare provider, with no one rejecting the idea entirely, suggesting that prognostic tools are seen as complementary.

When ranking sources of prognostic information, participants most often placed their neurologist at the top, followed by a combination of the tool and healthcare providers, with peers ranking lowest. This emphasises the neurologist's role as a trusted source while underscoring the benefit of integrating clinical expertise with digital resources.

Discussion

This study provides an in-depth understanding of how PwMS perceive and experience prognostic information and tools, highlighting the interplay between cognitive insight, emotional processing, and relational dynamics (18,19). Prognostic communication emerges not as a purely factual exchange, but as a deeply personal and emotionally mediated process (18,19). The findings emphasise that how prognosis is communicated can be as impactful as the content itself, echoing earlier insights into communication in chronic illness care (18,19).

A key finding is the foundational role of trust in enabling patients to engage with prognostic information. When patients felt their neurologist listened, respected their individuality, and demonstrated empathy, they were more open to confronting prognostic uncertainty. This reinforces the findings of McGinley et al. (2021), who emphasise that trust modulates patients' emotional responses and facilitates resilience in chronic disease (2). Celius et al. (2021) similarly stress that when patients feel respected and heard, they can better tolerate uncertainty about their disease course (4). In this study, trust did not eliminate uncertainty, but made it more navigable. Conversely, where trust was absent or where communication was perceived as superficial, participants tended to withdraw, postpone or avoid important decisions.

Despite the importance of trust, many participants described a reactive communication dynamic in which they had to initiate prognosis discussions themselves. This asymmetry created a sense of burden and abandonment, echoing Solari et al. (2010), who found that PwMS often experience silence or vagueness around disease progression (14). The finding raises concerns about the missed opportunity for timely counseling and confirms previous critiques of MS care as being overly focused on DMTs while underemphasising psychosocial support (3,9). Given the unpredictable nature of MS, patients need not only medical intervention but also a relational context in which their future can be safely discussed (1).

Participants expressed a strong need for clarity, not as certainty, but as direction. Prognostic information was valued for offering orientation and psychological support, even when outcomes were uncertain. This supports Dennison et al. (2016), who note that patients do not expect definitive answers but seek frameworks for planning and emotional preparation (19). The findings also highlight that timing and framing matter. Some received prognostic information too early, before they were ready, while others found it came too late, causing frustration. This underlines the need for flexible, patient-sensitive timing. In line with Köpke et al. (2018), a staged communication model is recommended, allowing repeated conversations tailored to patient readiness (15).

This study also resonates with emerging literature on disease progression in MS. The classical model of distinct MS subtypes is being challenged by insights into smouldering disease activity and PIRA (6,7). Such findings complicate both prognosis estimation and communication. Clinicians must acknowledge this scientific uncertainty transparently, without overwhelming patients. Participants appreciated it when healthcare providers acknowledged the limits of what could be predicted but still engaged in honest conversation about risks and possibilities. This is also supported by Degenhardt et al. (2009), who argue for the integration of clinical judgment and probabilistic data in MS prognosis (12).

With regard to prognostic tools, participants expressed conditional openness. Tools were not rejected, but their usefulness was seen as dependent on professional interpretation and emotional framing. These views support the concerns raised by Reeve et al. (2023) and Havla et al. (2024), who warn against the uncritical use of algorithmic prediction models in clinical care (16,17). The findings suggest that prognostic tools can play a meaningful role, but only when situated within a relationship of trust and contextualised by clinicians. Participants' reflections also highlighted the existential dimensions of prognosis. The tension between the desire to know and the risk of

distress has been explored by Hone et al. (2022), who advocate for careful screening of patients' emotional readiness before sharing prognostic data (3). The findings confirm that one-size-fits-all approaches are inadequate. Instead, clinicians should assess informational preferences continuously, recognising that needs evolve across time and disease stages.

The theme of self-determination was strongly present throughout this study. Participants wanted to feel involved in care decisions, including how much they knew and when. This confirms Solari et al. (2010), who found that autonomy in information management is a key predictor of patient satisfaction in MS care (14). These findings are also in line with Fernández (2013), who argues that individualised prognostic tools should be embedded in personalised care planning to support decision-making (8).

The use of a mixed-methods design was a strength of this study, allowing the combination of thematic depth with quantitative validation. Qualitative analysis captured the emotional nuances and symbolic meanings attached to prognosis, while the survey confirmed that a majority of participants had unaddressed needs for prognostic insight. The multidisciplinary team and use of COREQ enhanced the study's trustworthiness (20,21).

This study has several methodological limitations. The small, geographically constrained sample (n=16) limits the generalisability of findings. As participation was voluntary, selection bias cannot be excluded, particularly among those less inclined to engage in prognosis discussions. Although standard procedures were followed, the moderator's limited experience in qualitative health research may have influenced data collection. The quantitative component was descriptive and relied on self-report, introducing potential response bias. Finally, the Belgian healthcare context may limit the transferability of results to other settings.

These findings have several practical implications. Prognosis communication should be seen as an ongoing dialogue, not a one-time conversation. Clinicians need training in both MS and communication skills, including ethics and trauma-informed care. Prognostic tools can be useful, but only when used in a trusted relationship. Involving multidisciplinary teams, such as MS nurses and psychologists, can help connect medical information with emotional needs. Future research should explore how prognosis communication is influenced by health literacy, digital skills, and how patient preferences change over time and affect outcomes like distress and quality of life.

This study confirms that prognosis communication in MS care is not merely the transfer of information, but a complex and evolving interaction grounded in trust and attuned to patients' emotional and informational needs. When effectively delivered, it enables patients not only to understand their condition but to engage with their future more intentionally. The challenge is not only to predict outcomes, but to create space for patients to explore their meaning.

Conclusion

This study demonstrates that prognosis communication in MS care is not a neutral transfer of information, but a relational, emotionally charged process requiring sensitivity, trust, and timing. Through a mixed-methods approach, this research shows that PwMS value prognostic information not necessarily for its certainty, but for its potential to provide psychological anchoring and direction in managing their disease.

Trust in healthcare providers emerged as a key enabler of effective prognostic discussions. When care was empathetic and tailored, patients felt more empowered and emotionally prepared. Conversely, unclear or inconsistent communication often led to confusion, frustration, or avoidance. These findings highlight the importance of continuity, clarity, and emotional attunement in prognosis communication.

While prognostic tools were not rejected, their value was seen as conditional on appropriate interpretation and contextualisation by clinicians. Tools alone were insufficient, they gained meaning only within trusted relationships. This underscores the need to integrate prognostic tools into broader, patient-centred care models.

The study's strengths lie in its combination of qualitative depth and survey-based validation. However, its limitations include a small, self-selected sample and limited generalisability beyond the Belgian context.

In practice, prognosis communication should be reframed as a staged, dialogical process adapted to individual readiness. Multidisciplinary collaboration and training in communication ethics and trauma-informed care are recommended. Future research should explore how evolving patient preferences interact with digital literacy, emotional readiness, and outcomes such as psychological well-being and decision satisfaction.

Ultimately, effective prognosis communication enables patients not only to understand their condition but to actively participate in shaping their future within it.

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Supplementary Materials

1. Interview guide - MS-PERCEIVE study

Time	Slides	Topic	Person
18:00-18:15	1-9	Introduction	Sofie
18:15-18:20	10	Signing informed consent	Sofie
18:20 - 18:40	11	*Opening question* **Question 1** Go back in time to the time of your diagnosis. Can you describe the moment (or moments) when you received information about your own MS prognosis from your neurologist? How did it feel to receive or not receive this information? **Deepening questions:** • What emotions does it evoke to talk about your future with MS with your neurologist? How did you feel before the conversation? And how did you feel afterwards? • Was there a specific vision of the future that concerned you? • Did this conversation have an impact? In what way? • Did it feel like an affirmation, a surprise, a burden, a relief? Why? • Was this conversation in line with what you yourself expected or felt about your prognosis? • How did you deal with any uncertainties about the future? • Did you feel the need to do something immediately, such as ask more questions, look for information or talk to someone? • How clear was the information you got from your neurologist? • Did you think the information you received was sufficient? Why yes/no? • Were there things you would have liked to know earlier, more or in a different way? Were there specific words or phrases that reinforced the uncertainty? • How did you feel when you didn't get answers to your questions?	Ilse

18:35 - 18:55	12	**Question 2** Suppose you could or did have the conversation about your prognosis with your neurologist again, what aspects or factors could make you feel good about this conversation? How important do you think it is to get detailed information about your expected MS prognosis and why? **In-depth questions:** ● Do you feel you can easily discuss this with your neurologist? Why? ● How would getting more or less detail affect your way of dealing with de situation? ● What factors contributed to making you feel good about this conversation? ● What is it like for you to realise that you never had this conversation? What feelings does this evoke in you? ● Did you wait for such a conversation at the time, or was it something you did not consciously consider? ● What could/should a conversation about prognosis have meant to you? What would you do differently from last time? And why? What does 'detailed information' mean to you? What do you hope to get out of it? ● How do you feel about the idea that some information may not be fully available or ● predictable? ● Does more information make you calmer, or can it also create additional uncertainty? Why? ● If you had the chance to have that conversation again/again now, would you want to? Why? ● What would be the most important thing you would want to get out of it? ● How do you imagine the conversation would go? ● What might a doctor do or say to make it a valuable conversation for you? ● How do you deal with questions about your future that remain unanswered? ● Have there been times when you felt a	Ilse

		real need for more information, and how did you deal with that at the time?	
18:55- 19:25	13	**Context question 3**	Sofie
18:55- 19:25	14-16	**Question 3:** **Indicate that we are going to discuss some cases, but dare that they should try to reflect this as strongly as possible on themselves and how they would handle it in their situation. These cases show extreme scenarios and do not reflect reality; in fact, thanks to medical advances and better treatments, there is a greater chance of stability or even improvement.** **Case study 1 - outline the situation** Name: Lisa Age: 29 years old Child's wish: Yes Relationship: Yes, but lives alone Occupation: nurse in the emergency department Diagnosis: Relapsing Remitting MS Duration of diagnosis: established 2 years ago Prognostic tool: Digital tool indicates that there is a 70% chance of Lisa becoming wheelchair dependent within 10 years. **If you were Lisa, would you consider it important to get this information, despite the inherent uncertainty of the prediction (30%)? Why or why not?** **Would you trust the information from the forecasting tool? Why?** **If you think Lisa should know, how do you think the neurologist or healthcare provider would best share this information with her?** **Case study 2 - outline the situation** Name: Leen	Ilse

		Age: 40 years old Child's wish: No Relationship: No Profession: IT sector Diagnosis: Primary progressive MS Duration of diagnosis: established 10 years ago Prognostic tool: Digital tool indicates that there is a 90% chance that Leen will become dependent on a wheelchair within 5 years **If you were Leen, would you consider it important to get this information, despite the inherent uncertainty of the prediction (10%)? Why or why not?** **Would you trust the information from the forecasting tool? Why?** **If you think Leen should know, how do you think the neurologist or healthcare provider would best share this information with her?** **Case study 3 - Outline the situation** Name: Koen Age: 42 years Childhood wish: has 2 children Relationship: Married Occupation: Self-employed Diagnosis: Passed into a Secondary Progressive phase one year ago Duration of disease: Known to have MS for 18 years Prognostic tool: Digital tool indicates a 50% chance of Koen becoming wheelchair dependent within 15 years **If you were Jan, would you consider it important to get this information, despite the inherent uncertainty of the prediction (50%)? Why or why not?** **Would you trust the information from the forecasting tool? Why?** **If you think Koen should know, how do you think the neurologist or healthcare**	

		provider would best share this information with him? **In-depth questions for the case studies:** • What would the moment feel like when you were told this information? • How would this percentage affect your perception of your own future? • Does it make you feel pinned down to a particular future image, or does it leave room for hope/flexibility? • How does this prognosis change your sense of control over your life? • What would you do with this information? • Would you make different decisions obv this information? Why? • What would it change in the way you think about your future? • What impact would this information have on you? • What does 'knowing' mean to you? Is it better to be prepared, or does knowing less give you more freedom? • Does it feel like this prognosis 'takes something away' (hope, control), or actually helps you prepare mentally? • When would you experience a sense of reassurance?	
19:25-19:30	17	Summarise key findings (Deborah notes these on paper) + stop recording	Ilse
19u30	18-19	Explaining what happens with results + thanking them for their time, + introducing the survey	Sofie

2. COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	p. 6-7
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	p. 7
Occupation	3	What was their occupation at the time of the study?	p. 7
Gender	4	Was the researcher male or female?	p. 7
Experience and training	5	What experience or training did the researcher have?	p. 6-7
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	p. 6
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	p. 7
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator?	p. 7

		e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	p. 4
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	p. 4
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	p. 4
Sample size	12	How many participants were in the study?	p. 4
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	p. 4

Presence of non-participants	15	Was anyone else present besides the participants and researchers?	N/A
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	p. 4-5
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	p. 19
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	p. 6
Field notes	20	Were field notes made during and/or after the inter view or focus group?	N/A
Duration	21	What was the duration of the inter views or focus group?	p. 5
Data saturation	22	Was data saturation discussed?	p. 7
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	p. 7
Description of the coding tree	25	Did authors provide a description of the coding tree?	p. 8

Derivation of themes	26	Were themes identified in advance or derived from the data?	p. 6
Software	27	What software, if applicable, was used to manage the data?	p. 7
Participant checking	28	Did participants provide feedback on the findings?	N/A
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	p. 8
Data and findings consistent	30	Was there consistency between the data presented and the findings?	p. 8-12
Clarity of major themes	31	Were major themes clearly presented in the findings?	p. 8-12
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	p. 8-12

3. Survey Questions and Response Distributions on Patient Preferences, Concerns, Trust, and Use of Prognostic Tools among PwMS

Questions	Response Option	Count (%)
1. Was your prognosis (or expected course of disease) ever discussed during your appointments with the neurologist?	1. Yes No	12 (75.0) 4 (25.0)
a. If yes, who raised the issue of prognosis?	a. Yourself Neurologist MS nurse General practitioner Other healthcare providers Family member or friend Dont't remember	6 (50.0) 6 (50.0) 0 (0.0) 0 (0.0) 0 (0.0) 0 (0.0) 0 (0.0)
b. If yes, how useful did you find the information you received from your neurologist about your prognosis?	b. Not useful at all Somewhat useful Useful Very useful	1 (8.3) 3 (25.0) 4 (33.3) 4 (33.3)
c. If yes, did different healthcare providers give you the same or different messages about your expected MS course?	c. They gave roughly the same message They gave different messages I do not remember	6 (50.0) 3 (25.0) 3 (25.0)
2. Do you currently need more information about your expected course of illness?	2. Yes, a lot more Yes, a little more No, I have sufficient information No, I do not want to know I don't know	4 (25.0) 8 (50.0) 0 (0.0) 4 (25.0) 0 (0.0)
3. Which aspects of your prognosis would you like to know more about at this time? (more answers possible)	3. Probability that you will need a walking stick/wheelchair Chance of disease progression (secondary progressive MS) Probability of cognitive decline Probability of relapses Expected impact on daily activities and independence Expected quality of life Other, namely:	3 (18.8) 7 (43.8) 8 (50.0) 6 (37.5) 9 (56.3) 2(12.5)
4. Are you currently worried about what your MS prognosis is?	4. Not at all A little A lot	1 (6.3) 12 (75.0) 3 (18.8)
5. Do these worries affect your mood or daily activities?	5. Not at all A little A lot	7 (43.8) 9 (56.3) 0 (0.0)

6. Would getting more information about your prognosis affect your well-being?	6. Yes, this would reassure me (positive) No, this would make no difference Yes, this would make me anxious (negative)	9 (56.3) 1 (6.3) 6 (37.5)
7. In what areas would knowing your prognosis influence your decisions? (more answers possible)	7. Treatment Relationships Family planning Employment Financial planning No influence on my decisions Other, namely:	8 (50.0) 3 (18.8) 1 (6.3) 7 (43.8) 4 (25.0) 3 (18.8) 3 (18.8)
8. How much confidence would you have in a forecasting tool that predicts your disease course based on your medical data?	8. Very little trust Little trust Average trust High trust Very high trust	0 (0.0) 3 (18.8) 9 (56.3) 4 (25.0) 0 (0.0)
9. How reliable would you find a digital prognosis tool compared to the information from your neurologist?	9. I would trust the tool more I would trust the tool less I would trust the tool and the neurologist equally I don't know	2 (12.5) 7 (43.8) 4 (25.0) 3 (18.8)
10. How would you like to use this tool?	10. By yourself, without help Only together with a healthcare provider (neurologist, MS nurse) I would never use this tool	6 (37.5) 10 (62.5) 0 (0.0)
11. How much do you trust the following sources of information about your long-term forecast? (Rank from 1 = most reliable to 5 = least reliable) a. _____Een prognosis tool b. _____The opinion of my neurologist c. _____The opinion of another healthcare provider, side _____ d. _____The opinion of other people with MS e. _____A combination of a prognosis tool	11. Sequences (most reliable to least liable): 1. b-e-c-a-d 2. b-e-a-c-d 3. e-b-a-c-d 4. e-a-b-c-d 5. b-e-a-d-c 6. b-c-e-d-a 7. e-b-a-d-c	 5 (31.3) 4 (25.0) 2 (12.5) 2 (12.5) 1 (6.3) 1 (6.3) 1 (6.3)

and my neurologist or other healthcare provider		