




The “Journey” of Patients with Multiple Sclerosis in Greece—A Qualitative Study

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Abstract

Background: Multiple Sclerosis (MS) affects sufferers’ lives and requires everyday efforts to manage its challenges. **Aim:** The aim of this study was to explore MS patients’ lived experience of their “journey” in MS. **Method:** A qualitative methodology was adopted and semi-structured interviews with 17 MS patients, living in Attica and Thessaly regions, in Greece, were conducted. Research material was transcribed and analysed using Interpretative Phenomenological Analysis (IPA). **Results:** Analysis revealed five superordinate themes: 1) The journey to diagnosis describes the lived “journey” of patients with MS, from the first symptoms, to the main symptom and the diagnosis; 2) The image of the welfare state refers to participants’ experience with the health system and the welfare state; 3) Coping with MS describes participants’ efforts to identify and understand MS as well as their coping strategies; 4) Living with MS describes patients’ experiences of everyday living with the disease; 5) Doctor-patient relationship describes patients’ efforts to communicate with their doctors. Overall, it was found that MS dominated patient’s life. It was closely connected with disability, represented as “the wheelchair”, and perceived as “evil”. However, MS enhanced patients’ uniqueness and their sense of belonging to a unified group, with common understanding, clearly separated from all other healthy people. Patients experienced negative consequences at work, family relationships and everyday life. On the other hand, MS patients were eager to share their experience, support newly diagnosed patients, fight for patient rights and contribute in the change of stereotypes regarding MS. Views of the future included fears of losing autonomy and body control, uncertainty of the disease progression and worries of being dependent on others. **Conclusions:** MS constitutes a significant multitasking challenge to deal with. The “journey” could become smoother if specific health policy measures that were suggested by the patients facilitated their efforts to access qualitative services.

Keywords

Multiple Sclerosis, Interpretative Phenomenological Analysis, Qualitative Research, “Patient Journey”

1. Introduction

Multiple Sclerosis (MS) is a chronic demyelinating disease of the central nervous system appearing in four main types—Clinically Isolated Syndrome (CIS), Relapsing-Remitting MS (RRMS—85% of the cases), Primary Progressive MS (PPMS) and Secondary Progressive MS (SPMS) (MS International Federation, n.d.). It is estimated that a total of 2.8 million people live with MS worldwide (35.9 per 100,000 population), with an increasing prevalence in every world region since 2013 (Walton et al., 2020). In Greece, a 2-year cumulative period prevalence of MS was estimated at 197.8 per 100,000. In total, 21,218 patients (65.8% female) were identified (Bakirtzis et al., 2020).

Early and accurate diagnosis of MS is crucial to delay disease progression and improve patients’ outcomes (Tobin, 2021). Factors associated with delay in MS diagnosis include disease type, co-morbidity, type of symptoms and demographic characteristics (Mobasheri et al., 2020; Patti et al., 2022).

The appearance of a chronic disease such as MS in people’s life creates multiple challenges, regarding its management (Perrin Ross, 2013), including coping with diagnosis and the disease itself (Fallahi-Khoshknab et al., 2014; Holland et al., 2019; Messina et al., 2015); managing everyday living with MS (Bogosian et al., 2016; Burke et al., 2019; Haubrick et al., 2021; Kassie et al., 2021); fulfilling unmet needs (Galushko et al., 2014); dealing with (un)employment (Raggi et al., 2016; Strober, 2020; Vijayasingham & Mairami, 2018); addressing the impact of MS to family members and caregivers (de Ceuninck van Capelle et al., 2016; Neate et al., 2018; Topcu et al., 2016); accessing the health care system (Hadjigeorgiou et al., 2014; Mayo et al., 2021; Pétrin et al., 2021); taking decisions about medication (Stratos et al., 2020; Van Reenen et al., 2019); managing relapses and the consequent need for hospitalisation (Ghafari et al., 2014); dealing with emotion such as anger (Laing et al., 2020), anxiety and stress (Butler et al., 2019; Homayuni et al., 2021); and addressing the sense of self, dignity and the changes in the roles (Colaceci et al., 2021; Strickland et al., 2017; Žiaková et al., 2020).

According to the aforementioned findings from previous international research, MS poses multiple challenges to patients, covering almost every aspect of their lives. In Greece, available studies on MS have mainly addressed individual issues, such as access to healthcare (Souliotis et al., 2015), quality of life (Mitsikostas et al., 2021), work difficulties (Bakirtzis et al., 2021), and sense of self (Emmanouil, 2014); furthermore, all but one of these studies employed a quantitative approach. The present study aimed to fill this research gap by pro-

viding an in-depth understanding of MS patients' lived experiences throughout the entirety of MS patients' "journey" (Langgartner et al., 2005), namely from experiencing the initial symptoms, to MS diagnosis and treatment initiation, until the present day. The study also aimed to explore how MS patients make sense of everyday living with MS.

2. Method

2.1. Participants—Recruitment

To explore the lived experience of patients with MS in Greece, a qualitative approach was considered suitable. Participants were purposively recruited using an invitation letter, distributed by MS Patient Associations in the Attica and Thessaly regions, into their members, along with an Interest Form. MS patients who expressed their interest to participate informed their Association and signed the Interest Form, which was also considered as a consent for the Association to pass their contact details to the research team.

To be able to participate, patients had to fulfill the following inclusion criteria: 1) age 18 years or over; 2) be able to speak and understand Greek; 3) have been diagnosed with MS by a physician; 4) be able to provide consent. No other exclusion criteria were applied, e.g. relative to disease and treatment status.

Seventeen MS patients participated in the current study (12 women and 5 men). Their age ranged from 29 to 68 years and the time since diagnosis ranged from 6 to 23 years. Twelve participants lived in Attica and five lived in the Thessaly region.

2.2. Interview Guide

Research material was gathered through semi-structured face-to-face interviews, which lasted from 37 to 130 min (mean duration 66 min). Interviews were conducted by the first three authors (GK, health psychologist, Ph.D.; EK, health economist, Ph.D.; VT, health economist, Ph.D.) between November 2018 and February 2019, at a time and place chosen by the participants. All interviewers had previous experience in qualitative study. An interview guide consisting of open-ended questions was developed, based on a review of relevant IPA literature (Smith & Osborn, 2003) and similar "journey" studies of patients with breast and prostate cancer (Tsiantou et al., 2016, 2018) (Table A1). Interviews were digitally-recorded, anonymized and subsequently transcribed verbatim by an external party. Transcripts were then examined by the three interviewers against the audio recording to ensure accuracy. No repeat interviews were conducted.

2.3. Procedure

Before the interview, there was an informal conversation to build rapport. Interviewers explained the aims of the study and provided details of the interview (what they would ask, and the need for recording the conversation), particularly stressing the personal data protection and participants' right to withdraw from

the study at any time. Participants were given the opportunity to ask any questions.

Participants were asked to describe their experience living with MS, starting from the initial symptoms, the way they received the diagnosis and how they dealt with it. Then they reported how they manage different aspects of the disease (support seeking, access to healthcare system, relationship with their physician) at the present time. Finally, one question asked about their view on the future.

2.4. Analysis

Interpretative Phenomenological Analysis (IPA) (Smith & Osborn, 2003) was considered suitable to analyse the research material, as it is concerned with the individual's perceptions and interpretations of phenomena (Cockshott et al., 2021) rather than the phenomena per se (Smith, 2018). Analysis was performed by the three interviewers (GK, EK, VT), in three steps (identifying emerging themes in the first interview, clustering, and seeking similar themes to the following interviews), according to the relevant guidelines (Pietkiewicz & Smith, 2014; Smith & Osborn, 2003).

Initially, the first case (Alexandros) was separately analysed by all interviewers. The transcript was read several times in order for the interviewers to recall and become familiar with the atmosphere of the interview. When the preliminary emergent themes and the superordinate themes were identified, the three interviewers met several times to discuss in detail the way that codes had been developed and themes applied and agreed with the final names of the superordinate themes. This process allowed the reconciliation of the codes, as well as the naming of the superordinate themes, until researchers felt they adequately reflected the participants' experiences.

Following the above procedure, each interviewer analysed the transcripts of his/her own interviews. Subsequent meetings of the interviewers led to appropriate refinements of the themes, until final consensus was reached. Finally, all three interviewers discussed their preconceived beliefs about people with MS, in order to be consciously aware of their position within the research itself. Interviews continued until data saturation was reached, and no new themes were identified.

For the analysis, each participant was assigned a pseudonym in order to keep identities confidential.

Reporting of this study's methodology and results adheres to the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007) (Table A2).

2.5. Ethical Considerations

The study was approved by the Ethics Committee of the National School of Public Health, Athens, Greece (Approval 2119/20.06.2018). The Invitation Letter by

which participants were recruited provided information on the study objectives, data protection and mechanisms to ensure anonymity, the voluntary nature of participation and the right to withdraw at any time. All participants signed the Consent Form.

3. Results

The analysis resulted in the identification of five interrelated superordinate themes, including emergent themes: 1) The journey to diagnosis, 2) The image of the welfare state, 3) Coping with MS, 4) Living with MS, and 5) Doctor-patient relationship (Table 1).

Table 1. Superordinate themes and subthemes.

Superordinate themes	The journey to diagnosis	The image of the welfare state	Coping with MS	Living with MS	Doctor-patient relationship—care
Themes	<ul style="list-style-type: none"> - Primary symptoms - Accurate perception of the main symptom - Seeking care due to the main symptom - Announcement of diagnosis - Reactions to diagnosis - Coping with diagnosis - Looking for the causes 	<ul style="list-style-type: none"> - MS medication - Diagnostic and imaging exams - Medical monitoring: contact with health services - Psychological support - Physiotherapy & Exercise - Determining invalidity levels 	<ul style="list-style-type: none"> - Searching and evaluating information - To hide or to disclose? - Sources of social support - Coping strategies 	<ul style="list-style-type: none"> - Accepting MS - Consequences: implications - MS representations - Everyday life with MS - MS patients and others - Fears 	<ul style="list-style-type: none"> - Choosing the appropriate physician - Satisfaction with doctor-patient relationship - Guidelines for the way of living - Looking for the appropriate pharmacotherapy

3.1. The Journey to Diagnosis

This theme describes the lived “journey” of patients with MS, from the first symptoms, to the main symptom and the diagnosis. In this analysis, the main symptom was considered the symptom that motivated patients to seek medical advice. The key milestones of seeking health care and diagnostic testing to confirm the diagnosis were recorded and the characteristics of the diagnosis announcement, together with patients’ and families’ initial reactions when the diagnosis was announced, were captured.

Participants reported experiencing symptoms, years before (even since childhood) the main symptom leading to the diagnosis, which they currently associated with MS. Symptoms included numbness in the limbs, vision problems (double vision or sudden loss of vision) and symptoms related to the urinary tract. The periodicity of their appearance and their remission, in most cases, without treatment reassured the patients who attributed the symptoms to stress and the fatigue of everyday routine.

Regardless of the existence of prior symptoms, all but one patient experienced a persistent symptom, which motivated them to seek health care. In most cases,

this symptom was associated with numbness of the upper and lower limbs, lower limb motor problems or instability, severe headaches or dizziness and visual problems.

“The diagnosis was made because I had left hemiparesis from the beginning... I had both in my arm and left leg... it started one night, I felt an acute headache....” (Niki)

The persisting symptom and the pressure from family members motivated participants to seek health care, either from a General Practitioner (GP) or in the Emergency Department (ED) of a hospital (public or private). Criteria for being randomly referred to a doctor were doctor’s availability, distance from their place of residence, doctor’s contract to patient’s health insurance fund or to a hospital on duty.

“...my brother visited me and said ‘what’s wrong with you...?’ I said ‘I’ve got a cold’ and he said, ‘a cold and you’re like this?’ I said ‘yes. I had a cold and... back in the day’. And he said ‘can we go to the hospital and see?’” (Anna)

The first visit to a doctor or health facility did not always or directly lead to a diagnosis. In some cases, patients wandered around the health system and visited other doctors of the same or different speciality in order to receive a second opinion, as either the symptoms persisted or they had not received a satisfactory/sufficient answer.

“I’ve been going to doctors, looking into it, trying to tell what’s going on... I went to doctors who told me, there’s nothing wrong with you, it’s something that will pass... and they gave me a medication which didn’t, it didn’t do anything, it just made my condition worse.” (Marina)

How MS diagnosis was communicated differed in the narratives of participants, according to their age at the time of diagnosis, his/her psychological state at the time of symptom investigation, and the physician’s own certainty about the existence of MS. In some cases, the diagnosis was announced directly to the patient. In cases that the family members were informed first, some parents chose not to inform the patients in order to protect them from the “burden” of the disease, initially resulting to anger, but a later justification and understanding.

“...I didn’t know anything, because I was young... it was my dad’s decision not to announce anything to me. ...‘You won’t tell her anything if she doesn’t ask for it herself. ...Yeah, I accused him for a long time..., but then I changed my mind. I’m sure it was hard for him too, and he made a decision.” (Iliana)

Despite patients’ unique experience of how the diagnosis was communicated, some common features of the announcement emerged. On the one hand, doctors were usually sparing in the information they provided about MS; on the other hand, when they announced the diagnosis, they were usually calm, relaxed and reassuring, trying to encourage the patient and advise on how to proceed with his/her life from the diagnosis onwards.

“...don’t be scared, live normally, avoid too much sun and too cold, and we’ll talk, we’ll talk... I promise you that you will live, don’t worry about dying be-

cause you have MS, I just want to watch you and I want to see how the disease progresses, that's it... The treatment of the Professor was, 'put the MRIs on a shelf, don't bother again.'” (Angeliki)

On hearing the diagnosis, patients experienced a variety of contradictory emotions. Some felt relieved, as the previous investigation of symptoms was completed, the existence of MS was verified and patients knew what they had to deal with.

“I calmed down, a weight has been lifted. That is, what I was searching for, that I didn't know, this uncertainty, I didn't know what I was fighting with.” (Olga)

On the other hand, some patients experienced fear and anxiety about the unknown, uncertainty about the progression of the disease, and ignorance or inability to understand it. The association of MS with disability that emerged with the announcement of the diagnosis contributed decisively to their initial reactions.

“...the first few days were shocking, because I tell you I had heard about MS and I always combined it with a wheelchair and a not too long-life span of the patient.” (Efterpi)

The announcement of the diagnosis also turned the lives of the families, whose members also experienced unique emotions, predominately fear, anxiety and shock.

“...and my wife, when she heard it, she cried.” (Peter)

Along the way, until they accept and cope with the MS, patients had to decide about the future course of their health and manage the new reality. Some experienced a period of denial during which they did not follow the doctor's instructions, or avoided being informed. Others were numbed, underestimated the existence of MS, and went on with their lives as they did before the diagnosis.

“To my ears, I don't... ...everything sounded normal. Everything normal, everything is nothing to worry about (laughter).” (Anna)

The search for meaning and outbursts of anger at both loved ones and oneself were typical reactions.

“A little bit of anger, a little bit of, uh..., why not be healthy, why not like my peers mostly, all that. Why do all these things happen, that it's going to come down to.” (Nikos)

For many participants, a positive assessment of the situation, characterised by calmness, optimism and a belief that they would cope with any situation, followed the initial shock.

“It was shocking, yes, because I didn't expect that, but from the first moment I saw it quite positively I would say... ‘we will see, we will put down all the factors, the situations, everything and I will see what to do’...” (Efterpi)

The confirmation of MS through the announcement of the diagnosis was the starting point for patients' “journey”. As they recounted the beginning of this “journey”, they returned to the past seeking the causes of MS. Inevitably, they reflected on their own mistakes or omissions, health system deficiencies and in-

tense pace and demands of modern life that led to the onset and progression of the illness. Patients focused on their inability to make personal choices, set boundaries and protect themselves, thus blaming themselves for the onset of the disease.

“From the situations, the environment...in fact I did not set limits. I didn’t protect myself as much as I should have protected myself...Since I chose to have MS...to have something to deal with, let me have the MS I want...Because I actually unconsciously chose to have MS.” (Niki)

3.2. The Image of the Welfare State

This theme reveals participants’ experience with the health system and the welfare state, the problems faced by participants, the economic impact and how the provided services affected their daily life. Specific ameliorative suggestions were also recorded.

Three dimensions of access to pharmacotherapy were considered of major importance and highlighted by patients: prescription, dispensing and co-payments and availability of new medicines. Prescription of MS medication was considered the easiest of the dimensions, since prescriptions were valid for up to six months, thus patients avoided any unnecessary discomfort. Nevertheless, as medications were dispensed predominantly from the National Organization for the Provision of Health Services (EOPYY) central pharmacies, this resulted in many queue hours and access barriers, especially for those living at the islands.

“I take my injections for MS every month from the EOPYY’s pharmacy. It’s chaos... endless queues and you have to wait for over an hour.” (Olga)

Regarding co-payments, participants felt very lucky since their medicines were fully reimbursed. However, as the cost of many other additional medicines (i.e. antidepressants) to face MS complications was not fully reimbursed, the economic burden resulted in increased stress.

“We pay a lot in co-payments, up to 100 - 150 euros per month for the pharmacotherapy of concomitant diseases... Every day we are in a constant stress, how are we going to pay for all these medicines.” (Olga)

Availability of new and innovative medicines was also an issue of great concern, since the slow approval procedures were an additional barrier to their access to better pharmacotherapy.

“We don’t have access to the newest medicines as the European patients do... we wait two years now... why? Is the problem economic?” (Ira)

Diagnostic and imaging exams were fully reimbursed only in public hospitals, otherwise, these were subject to co-payments (25%). Participants turned to private diagnostic centres, especially for their imaging tests in order to avoid public hospitals’ waiting lists and delays. Timely access to MRI scanning was particularly important when patients experienced a relapse of the disease, and they needed to take an MRI in a short time frame.

“I go to private centres for my MRI scans. The co-payment is around 80 euros, but...health is a priority...” (Iliana)

Overall, most of the participants were not satisfied by the quality of services provided in public hospitals due to shortages of medical supplies, access barriers for people with mobility problems, long waiting lists, rudeness of some health professionals and the need for indirect payments in order to receive quality services and skip the waiting lists. Thus, they chose the private health sector, believing that these health services are safer and of better quality.

“...we have to admit it. In the private health sector, you have better care... doctors stand by you all the time...even the medication is in the right dosage as it should be... this is my impression.” (Ryan)

Many participants stressed the need for a holistic approach of the disease with a team of experienced health professionals, trained in the needs and demands of the MS patients. Therefore, they chose hospital neurology clinics with an expertise in MS, where they felt safe.

“...Now, I go to a neurology clinic specialized in MS in a public hospital and I feel safe... I go alone, because I'm not scared that I will be forgotten.” (Artemis)

Although all patients recognised the importance of psychotherapy during their “journey”, only a few had received professional psychological support, due to its considerable cost, as these services were not reimbursed by social insurance and their provision by the NHS is inadequate.

“We need the help of psychologists... during the hospitalization and the pharmaceutical treatment, but in the hospitals, there aren't any... and this is wrong, very wrong.” (Athina)

Regarding physiotherapy, patients emphasised the low number of sessions reimbursed by social insurance. Although this issue was resolved during the study, additional barriers such as the increased cost and the lack of MS-specialised physiotherapists and centres remained. In order to overcome these barriers, some participants joined self-help and physical activity groups offered by MS Patient Associations.

Participants referred to the Disability Certification Centres (KEPAs)—the responsible institution for determining and certifying the degree of disability—as one of the darkest chapters in their life, besides diagnosis. Various problems were reported, ranging from applying for the disability benefit to undergoing the medical examination and determining the disability levels. The collection of the required medical documents was taking time and money and needed to be regularly repeated; the medical examination from a Committee on a specific date following the application was never actually happening, and the disability levels were determined upon just patient's medical record and clinical picture. Patients asked for a total reform of the KEPA's operation on the basis of patients' respect and the modern disability policies, providing more than strictly financial benefits, such as encouraging the hiring of disabled people.

“The medical examination from the committee is ridiculous... The committee's neurologist didn't even check my medical record. He just looked at me, asked me a couple of questions irrelevant of my condition and he said ‘OK...’ and he said ‘the disability level is 20%’.” (Efterpi)

3.3. Coping with MS

This theme describes participants' efforts to identify and understand MS as well as their coping strategies.

Seeking information about MS was crucial for participants in order to define and comprehend the disease and consequently to maintain control over it. Internet, social media, health professionals and Patients' Associations were the main sources of information about pharmaceutical treatment and daily life with MS. Patients evaluated the acquired information, especially those from the internet and social media, and questioned its validity.

"Yes. Uh... the first year, mostly yes, from the Internet uh... and from my doctor of course... I was listening to my doctor, of course... I was talking to her." (Nikos)

Disclosure of the disease was a major decision for every patient, connected with beliefs and attitudes towards MS and the need for social support. Social disclosure was thought to be necessary, as it had a positive impact on a personal level, yet this was a difficult decision due to the stigma and the guilt accompanying MS.

"Previously, if you said to someone that you have MS, they were speechless, now we can discuss it openly, and it is the right thing to do." (Angeliki)

Immediate disclosure of their health status to the loved ones (family, kinds, friends), was part of patient's identity, leading to preparation for future health deterioration.

"I don't think that I have to hide it. I don't find a reason to do so, because in the future I may need a cane, more people will see my situation." (Efterpi)

Disclosure to the kids differed among patients, who considered kids' age in order to disclose their disease.

"My older son knows about MS. The younger one knows that my feet hurt... I'll tell him, I don't mind." (Peter)

Disclosure to friends depended on the strength of friendship and the level of trust. All participants mentioned that their friends' initial reaction was not as supporting as expected, probably due to the deficit of information regarding MS.

"Then, to my friends... and so on, but everybody said "what is this?", "what is this?", nobody knew, nobody knew." (Athina)

Some patients disclosed MS to the work environment, either because they felt safe or due to a sense of work ethics.

"I said it from the very first interview that (uh) I told them 'you know what? I have that, as you can see, it doesn't affect me at the moment. That doesn't mean that later on we won't have some difficult days possibly and I'm just telling you because I want to be clear with you.'" (Alexandros)

Concealment was more common at the first period following diagnosis, mainly due to low self-esteem, non-acceptance of MS, stigma and fear of social isolation.

"I was hiding MS from everyone...I felt that they would see me different if they knew, through our discussions, I understood that they saw disabled people

as a burden for the family.” (Olga)

Social support was important for the participants in order to face MS. Family, partners and friends, the self, health professionals and co-patients, as well as spirituality were mentioned as sources of social support.

Patients’ family was the most significant source of social support, providing practical help to deal with everyday challenges, and acting as a model for the effective management of the disease. Nevertheless, family was not always supportive, mostly due to the family’s denial to accept MS.

“My mum, has gone through a lot with her health. She was my role model and maybe I’m like her... She always had a big smile... we never heard her complaining... She was always very strong and calm... I believe that I learned a lot from her attitude towards her illness.” (Olga)

“What is it? They don’t help me... They were saying to me that I was lying, that I’m fine...” (Niki)

For the majority of the patients, friends stood by them, encouraging and motivating them in order to face MS. When friends were absent, patients felt frustrated.

“I disclosed my disease to my friends, but I didn’t find any support (laughing), because most of them don’t know, and they don’t want to find out...” (Nikos)

The support of co-patients was vital. Co-patients provided information and practical and psychological support through organised programs. They reinforced the feeling of belonging to a team and created strong relations that had a major positive impact on patients’ health.

“There are people there [in the Patient Association] who... offer to you what you really want, what you miss. If you don’t know where to find something, you can ask the people in the Patients Association, and they can help you.” (Michalis)

Psychological support was vital. Psychotherapy provided the opportunity for a quick start of management, emotional relief and self-awareness.

“Yes, it helped me a lot, because since 2013 and until now I’m doing psychoanalysis... uh, it’s very good for me. Because psychotherapy is therapy for MS... and I’ve found that out, and that’s why I think I’m doing pretty well. Uh... because I’m good inside.” (Niki)

Patients used various coping strategies in order to face the MS challenges. Some focused on the present, reappraised their life positively and adopted a life attitude where the “here and now” motto prevailed.

“...at the same time, I say: ‘Stop. OK, you’re fine, you have your family, your children, your husband, they’re fine too... You have to have a great time, to live the moment, every moment.’” (Afroditi)

Some faced the problems directly and searched for solutions to improve their daily life and their quality of life. Regular check-up and the prioritization of health helped them to keep the control over the disease and prevent disease relapses.

“...Because I’m very stubborn, ...I kept standing up, I told that I won’t sit

down. And I think that this attitude helped me a lot. ... I have a regular check-up ... I never skip my exams...” (Niki)

Some patients adopted a realistic approach and belief that new medicines will appear in the near future, eliminating MS, while others chose to focus on the positive aspects of MS, using mainly cognitive bias to form an opinion about MS and the severity of its implication on their life.

“And now we expect so many new medicines... when 2020 [she mentions the name of a drug] and two more drugs will come... it's very important. I believe that someday MS will stop to exist.” (Niki)

“...now I say to myself, OK I'm alive, thankfully I don't suffer from a stage IV cancer.” (Afroditi)

Evaluating and redefining their relationship with significant others seemed inevitable. Setting boundaries with their family members, friends and the self helped patients to keep their autonomy and a sense of control over their health. When boundaries were broken, patients learned from the consequences.

“I think that I should take care of me more. I take care of all others, but not myself... I listen to everyone, but not me...boundaries, psychological boundaries.” (Ira)

Unconscious defence mechanisms such as denial, avoidance and idolisation of the period before diagnosis were adopted.

“...and she (her doctor) told me that a girl, who had the same disease as I, was married yesterday. ... And I looked at her and I said, “Why should I care?” (Niki)

Some participants realised major deficits in the Greek society regarding MS information, inclusion and respect for diversity. Thus, they expressed their intense need to be MS's ambassadors, participating in Patients' Associations' actions, acting as a role model, informing, supporting and advising the new-diagnosed patients, demanding patients' participation in health policy decision-making, fighting for the acceptance of disability and diversity and making Greek society aware of MS.

“...I have the opportunity to help other people, discuss, give advice.... That's what I'm trying to do, to convince people to see beyond the first image... I would like the society to have a different approach towards the disabled, to be more sensitive... So, I want to be involved more in this kind of actions and I hope that I'll be able to make things different and do something good for my co-patients and the society.” (Alexandros).

3.4. Living with MS

This theme describes patients' experiences of living with MS. For participants in our study, the disease represented a turning point in their lives and those of their families, with multiple visible consequences for relationships, social life, work, daily life, self-image, etc. At the same time, participants' narratives highlighted representations of MS and their fears for the future.

Acceptance of MS, as an established reality in the participants' lives, did not necessarily happen at the time of the diagnosis. Accepting MS as part of their lives

was a difficult task, a continuous struggle to live a life with the least possible limitations.

“No, I’ve been over this for many years, I mean everyone has his own path as a patient. If I’m going to end up in a wheelchair at some point, OK.” (Olga)

Accepting MS of their loved ones was a challenging gradual process for the participants’ close and extended family too, expressed as excessive worry, fear, overprotection, even as rejection, grief and shame. Especially for children, trying to accept the reality of MS brings out worry, fear, disappointment, emotional outbursts and avoidance attempts.

“The elder one... keeps it all inside, of course...um... he will have an outburst. The younger one may cr...” ‘Mom, why does your leg hurt?’ and cries. The elder one will say, ‘Enough with the crying, stop!’ and he will go to his room.” (Afroditi)

MS brought an upheaval to both the patients’ and their families’ lives. For some participants, MS redefined family roles and significantly affected their sexual relationships. Many patients worried, avoided entering love relationships or having sex, or had painfully experienced rejection in the relationship. In this study, only one participant touched upon the impact of MS on sexual life, speaking in general terms.

“I’d say, the sexual part. One aspect that we didn’t mention, ...it is a very important aspect ... sexual relationships, very important, but because there are still... uhm...taboos here in Greece, we don’t talk about it, and it’s very wrong because many young people with this disease are suffering, they are afraid, they don’t talk about it, they don’t make a move to be with a girl... We are an organism that can burst and explode.” (Ryan)

For some participants, MS brought upon important adaptations in their social life and set restrictions on everyday life and habits, due to patients’ deliberate choices to adapt practices to the requirements of the disease.

“I once was... I wanted to go out, I would get home from work at 23.00, I would take a shower and me and my husband would go out with friends. I cannot do that anymore. Even though I don’t work, I cannot do it...” (Afroditi)

Participants acknowledged the importance of and the difficulties in having a job—or even just being in the work environment, in order to maintain a sense of normality or in having a future prospect and strived by all means to stay on the job.

“For me, it would be much better if they put them [MS patients] in some positions, that is to hire them, because work is a very important part...I didn’t work for one year and I got crazy staying at home.” (Elpida)

Participants reported a general worsening of their health status due to MS. Some described experiencing MS-related mobility problems plus depression, as well as attention and/or emotion problems. Others experienced MS consequences as multiple losses: their self-image, social life, and their roles as parents and employees.

“...so when you see that they’re closing doors because you have... an issue, you

start saying: why? What happened? Now why do I have to pay for it? It's not enough that, I have lost a piece of my life, why should I lose more, more, more?" (Alexandros)

Most participants had formed MS representations and perceptions through their contact with patients in their wider social environment that surfaced when MS entered their own lives. MS was perceived as a mind game, a wake-up call, a chance to change past behaviour, a possibility to redefine relationships, an opportunity to mature. At the same time, patients brought forward the multiple "faces" of MS, mostly negative ones. MS was something "*unknown*", even for the specialised health professionals; it was perceived as "*menace*", "*devious*" and "*dark*", "*invisible*", "*erratic*" and "*unpredictable*", a disease that progressed quickly, especially in children. It was a painful "*battle*", a "*trial*" for strong people sent from God, whose positive outcome could make them proud; it was the externalisation of repressed feelings, an inner enemy that attacked oneself. However, the dominant representation of MS both among patients and their family was that of a physical or cognitive disability, an "*evil*", which is accompanied by an intense stigmatisation.

"You have to understand that MS is the disease with a thousand faces." (Angeliki)

MS seemed to be almighty and dominate patients' lives, overshadowing any other (health) problem. Some patients painfully experienced the loss of control over their body, whereas fatigue was like an actual and a symbolic "*weight*" in their everyday life. An equally critical part of their everyday life was the management of MS relapses which take participants by surprise, put them out of their routine, and thwart their plans. They are an intense and painful experience, leading to depression and exhaustion.

"I mean, to catch things and see them fall from your hand, that was the most difficult part. I had to manage that." ... It is a relapse, we'll flash..." ...I mean, it's a little unsettling right now with the flash and all, but okay, we'll get back into the routine." (Olga)

An important challenge for patients' everyday life was to meet specific needs such as social interaction, participation in athletic/recreational activities, travel, and work. Those who managed to meet these needs felt substantial satisfaction.

"...I was asking [the doctor] certain things, if I can go on a trip there, if I can do this or that... because I am not the one to stay at home, and ...not to have contact with people, ...I got crazy, I said 'I am going to sit here and do what?' I was opening the closet and... 'when am I going to put these clothes on? When will the phone ring for me?'" (Angeliki)

The cost of medical visits, medication and other aspects of managing MS was a critical manageable issue for patients, yet some others struggled to deal with it. Having insurance coverage for tests and medicines, receiving a disability allowance or a pension, and availability of other sources of income in the family enhanced the sense of control over costs. When patients could not cope, they experienced severe stress and prioritised their needs, resulting in some needs being

unmet.

“Yes, ...you have to visit the doctor, you have to have money, absolutely, no matter what. This is a burden. Since I can't work—of course now I'm waiting to get my pension. How do I cope? How? These doctors, I have to pay them if I want to visit their practice...” (Athina)

Some participants referred to the uniqueness of being an MS patient, which was clearly captured in the way they described the MS patient group. At the same time, the main element that differentiated them from healthy individuals was their empathy and concern for other MS patients, and their different needs.

“When you are a patient, and you meet another patient, immediately there is an intimacy, that is, you become part of another [contemplates], not a scale, another list of people. We also met today, it's not the same.” (Iliana)

Having MS triggered a variety of fears, especially when patients projected their lives into the future. The dominant fear was related to the progression of the disease and the subsequent deterioration of patients' physical and mental health. Fears regarding the prospect of disability and loss of autonomy were associated with existing MS representations and expressed clearly or indirectly. For some, their fears led to a vicious circle of inaction and limitation of activities relating to their social life.

“There are times when... there are times that I am scared of how this might turn out (uhh)...” (Alexandros)

3.5. Doctor-Patient Relationship—Care

Following their diagnosis, most patients began a search for a doctor who would become their treating physician and monitor their condition. Some stayed with the doctor who diagnosed them whereas others changed one or more doctors, at some point in their “journey”, due to a personal choice, financial barriers, doctor's move to another area, and a change in the participant's place of residence. A variety of factors were considered when choosing their treating physician: the reputation of the doctor or the hospital, the easiness/difficulty of access (geographical or other), the recommendations from the social environment or other health professionals, the affordability, and patient's own impression from previous contact.

“I've known him since he was an intern and (um) because I know the background he has through his resume, all this, I trust him... That's what made me... choose him.” (Alexandros)

The relationship with their doctors was of crucial importance, since the doctor was a source of information and support in the course of their life with MS. The quality of communication was a critical factor in this relationship; providing information about MS and treatment using simple language, the doctor's willingness to spend time and answer patients' questions—especially on sensitive topics-, his/her responsiveness to the patient's relapses and treating patients as equals in decision-making were the most important communication dimensions that made participants feel fulfilled. Conversely, communication deficits led to test-

ing/questioning medical knowledge, compromising satisfaction, or the decision to search for another doctor.

“But this helped me a lot. This, knowing that I will call her at any time of the day, and she will pick up the phone—she did this with all her patients-, that helped me a lot psychologically... I had no insecurity...” (Olga)

Doctors provided instructions for the management of MS in two levels: the lifestyle (i.e. advice on diet, frequency and type of exercise, stress management) and the appropriate medication. The extent to which patients followed their doctors' instructions varied. Some patients followed recommendations in their entirety, while others prioritised and focused on some areas.

“...in terms of nutrition, I want to be... not to have deficiencies in my diet... No, I've forgotten a bit about exercise. I want to go to the gym sometime, to work out. Basically, just Pilates. I used to do some yoga, but then I stopped.” (Marina)

Medication was one of the main ways of controlling MS progression, together with the maintenance of good mental health and physiotherapy. Early initiation of pharmacotherapy was crucial, while the reported delays in initiation were not due to patients' own decision. Only two female participants expressed negative attitudes towards receiving pharmacotherapy due to the fear that a future pregnancy might be affected (Athina), and the subsistence of the symptoms (Artemis).

“I see myself, how I was without the treatment and how I am after taking treatment. I'm more stable now, no relapses (uhm) so I adhere to it.” (Alexandros)

Regardless of when and how treatment was initiated, participants, along with their treating physician, were searching for the appropriate treatment regimen. The main criterion was the effectiveness of the medicine in terms of delaying the progression of MS. The body acted as a “*mirror*” of the effectiveness and a guide for the MS management. Participants monitored their body's reactions and evaluated the treatment from their own perspective. A new relapse, severe side effects or side effects that were no longer acceptable to the patient were reasons for switching to another medicine.

“...according to, and together with the doctor we see it, from the tests it seems that it is going well, I see it in myself that it is going well...” (Alexandros)

Some participants reported high levels of adherence, even to injectable treatments or those causing adverse effects. In some cases, patients discontinued treatment in cooperation with their doctor, either because they no longer benefited from the available treatments or because of co-existing health problems; they then placed their hopes in the new treatments that were expected to become available in Greece.

“They tell me, there is no medicine for my case. There is one, but you can't, he tells me, take it because you have [mentions a health problem]. So far ok... It is stable. It is stable. We are now waiting for the new medicine that will come from the US next year...” (Afroditi)

4. Discussion

The current study described the lived experiences of patients through their “journey” with Multiple Sclerosis. The participants narrated with great composure, and without emotional stress the events related to their diagnosis, especially when referring to medical issues. Sometimes, they even joked about various situations that occurred at the beginning of their “journey”, probably due to the long time that passed from the first symptoms and the intake of the interviews. Nevertheless, they felt emotionally disturbed when they narrated the distress of their family before and immediately after the announcement of their diagnosis, as well as their concerns about the pain they might cause to their family members because of MS. In some cases, this could even be described as guilt-ridden, as it sets aside patients’ personal fears of their future after the diagnosis (Fallahi-Khoshknab et al., 2014).

When the diagnosis was made before having children, a fear was triggered because of the possibility of not being able to have children and start a family—this fear was also manifested at later stages of the “journey”, for example, in the decision to start treatment or to stop treatment in order to start a family (Ghafoori et al., 2020). In cases where patients had children, fear and anxiety about the future of the children were manifested, as the parent was called upon to respond to the role of protector of the children and autonomous member of the family under particularly difficult and unprecedented circumstances for the whole family (Haker et al., 2022).

The announcement of the diagnosis ended uncertainty, the sense of irregularity, the agony of the investigation and the suffering of medical examinations. The initial numbness of the diagnosis was followed by a plethora of emotions, dominated by fear of the new reality and the difficulties of everyday life, and anger both towards others and themselves (Topcu et al., 2023). The calm perspective of the new situation, and the search for realistic solutions to deal with present and possible future problems was a fact for a portion of participants who were immediately activated and sought information and support in order to understand the disease and to plan to deal with it (Holland et al., 2019). The diagnosis was an equally traumatic experience for patients’ family members, who were trying to find their way in the new circumstances. On the one hand, they tried to manage their own fears and fight against the social representations of the disease, and on the other hand, they tried to stand by their own person as helpers and companions (Uccelli, 2014). This effort was not always successful, yet all patients recognised that a positive attitude on the part of the family was a catalyst for the smooth management of MS.

The need of patients to know and understand MS and its characteristics was crucial for the overall management and the integration of the disease into their lives. Therefore, one of the key strategies used by the participants was to seek information from various sources, which along with the other strategies had the ultimate goal of enabling the participants to gain and maintain a sense of control over their MS (Berhanu et al., 2023). It seemed that health literacy was high, sat-

isfatory and functional for the participants in the present study, who, not only were able to seek information, but they could also evaluate and utilize it to the extent that it was helpful to them (Dehghani, 2021).

Disclosure or concealment of MS in the family or the wider social and work environment was an equally critical milestone—along with diagnosis—in the life history of patients. Their choice to disclose or conceal their disease was strongly linked to attitudes and stereotypes around MS, as well as to patients' previous experiences, and aimed to seek and secure the all-important social support (Leavitt et al., 2024).

The emergence, awareness and acceptance of MS as a reality in participants' lives constituted a substantial upheaval of many aspects of their everyday living as well as their families', resulting in a constant struggle to maintain previous normality. The onset of MS brought about multiple consequences for patients, both on an emotional level, in relationships with intimate/friends, sex life, having children, social life, work, daily activities, self-reported health status, self-image and financial situation, which participants were challenged and tried to cope with, in a variety of ways (Bogosian et al., 2016; Burke et al., 2019; Haubrick et al., 2021; Kassie et al., 2021). Especially for sexual life, perceptions, representations and stereotypes around MS and sexuality impacted future partners' reactions and made it difficult to speak openly about these issues (Altmann et al., 2021).

The current study recorded a variety of social support sources. Participants' social support network included significant others, namely family members, partners and friends, self, health professionals, other MS patients and religion, each covering different needs (Papa et al., 2021; Ratajska et al., 2020). Additionally, participants reported adopting a wide range of strategies to address the challenges posed by MS, namely cognitive reappraisal and assertive problem solving, for the practical issues posed by MS and denial, avoidance and euphoria to managing emotions (Holland et al., 2019; Homayuni et al., 2021; Laing et al., 2020).

Participants highlighted multiple perceptions and representations of MS, the majority of which had a negative connotation. The disease was represented as "evil", "unknown", even for experts, and perceived as a "scourge", "insidious" and "dark", "invisible", "unpredictable" and "unpredictable". It was thought as a painful "battle", a "test", from God, for strong people, the positive outcome of which can make them proud (Luca et al., 2022; Vaughan et al., 2003). However, the dominant perception, prevailing in both the participants and, through them, the wider family and social environment, was that of MS as a physical and mental disability (Lo Buono et al., 2023), with a high potential to happen (Boeije & Janssens, 2004). This perception was explicitly expressed by the word 'wheelchair', which contained a strong element of stigmatisation and a sense of discrimination (Ochoa-Morales et al., 2021) and largely determined both the everyday practices of patients and their relatives, the adopted coping strategies and mechanisms, and patients' attitudes towards institutions and social care policies.

When participants talked about their future, they expressed lived fears, the most prevalent of which was that of poor disease progression and the subsequent deterioration of their physical and mental health, which would lead to a loss of autonomy through dependence on other people (Dehghani et al., 2019). At the same time, it became clear that living with MS created a unique identity—that of the MS patient, which put participants “together” with other MS patients, and, above all, gave them a clear differentiating role in relation to the “others”, the non-patients with MS (Barker et al., 2019). This identity made patients to develop a strong eagerness to support newly diagnosed patients, fight for patient rights and contribute to the change of stereotypes regarding MS indicate the potential MS to lead to a post-traumatic growth (Gil-González et al., 2022).

Management of MS requires the coordination and collaboration of many health professionals to provide comprehensive care to patients (Clavelou, 2013) and access to new treatments (Nadeem et al., 2016). Interactions of health care professionals with their MS patients need to be fully understood (Soundy et al., 2016), although interpersonal relationship with their physician has been recorded as good (Thompson et al., 2022). Nevertheless, the lived experience of Greek patients and their overall contact with the Greek health care system highlighted the need to improve health care services (Hadjigeorgiou et al., 2014; Souliotis et al., 2015). Specifically, patients suggested simplification of the procedures for the procurement of medicines, improved access to professional psychological support and specialised physiotherapy and establishment of MS clinics. Additionally, out-of-pocket payments such as co-payments for medicines (other than those for MS) and MRIs, direct payments for physician visits, professional psychological support and physiotherapy were common for participants, constituting a barrier to care and causing financial hardship, as a previous quantitative study also found (Vozikis & Sotiropoulou, 2013).

4.1. Strengths and Limitations

We evaluated the strengths and limitations of this study in the light of the four principles for assessing the quality of qualitative research (Yardley, 2007). Regarding sensitivity to context, we tried to provide the reader with a detailed account of the experiences of the participants, using as many experiential expressions and quotes as possible. As far as commitment and rigor, this study was conducted by a team of researchers with different, complementary backgrounds, such as health psychology and health economics, allowing exploring the different aspects of the experience. Transparency and coherence were achieved by presenting a clear overview of the methodology, and the theoretical foundations of the study. All three interviewers kept notes regarding their experiences, expectations and prejudices and discussed how these could influence collection and analysis of the research material. Finally, regarding impact and importance, we think that the study made a significant contribution to MS patients and the health care system as it is the first and only qualitative MS study in Greece, allowing an in-depth understanding of the lived experience of MS patients.

On the other hand, the study was not without limitations. Due to its qualitative nature, it is not possible to generalise the findings. Additionally, all participants were related to Associations, thus they benefitted from established network-related support. This might result in a potentially positively skewed estimation of their illness perception and the quality of care and support they received.

4.2. Implications

This study provided a unique insight into MS patients' lived experiences and offered a deeper understanding of their needs. From a policy design perspective, decision-makers could redesign the basic healthcare structures so that they become more patient-focused and intervene with targeted initiatives to alter aspects of insurance coverage so that MS patients enjoy all benefits to help them manage their disease. Health practitioners working with MS patients could consider these findings so that they create a multidisciplinary team approach within clinics and other health settings, so that they can effectively support MS patients, family and friends throughout their "journey"—from diagnosis to long-term management.

Future researchers could further explore the unmet needs of MS patients by using either a quantitative methodology with a representative sample, or a mixed-method approach. Additionally, since MS practitioners are crucial in MS management, future studies could investigate how MS burden of their patients affects their own health and well-being.

4.3. Conclusion

MS prevailed in patients' lives. Patients adopted a wide range of coping mechanisms to deal with MS, yet they faced systemic shortages in the Greek health system and obstacles in covering their health needs.

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This article is dedicated in the Memory of Professor Emeritus John Kyriopoulos.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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Appendix

Table A1. The interview guide.

<u>Past (looking backwards)</u>	Initial symptoms-diagnosis	When were you diagnosed with MS?
		What motivated you to go to a specialist?/Was she a doctor?/Did you go to a healthcare service?
<u>Present (looking at "today")</u>	First reactions	How long did you have these concerns or symptoms (before you visit a specialist/healthcare service)?
		What was the specialisation of the first doctor you visited?
		Why did you choose the specific doctor?
		What kind of diagnostic tests did you run?
		How long did it take from the time of your first contact with the doctor until the diagnosis?
	Information and decision-making about treatment	Do you think there were delays in your diagnosis?
		• If YES, why did these happened?
		What were your first thoughts when you heard the diagnosis?
		What did you think about your body/about yourself?
		What did you know about MS before the diagnosis?
Doctor choice	Some patients feel the need to share with their family or disclose the diagnosis to their environment, while others do not. What was your experience?	
	What was the reaction of your friends/relatives?	
	How were you informed about your disease/treatment options?	
	How satisfied were you with the information you received?	
Treatment	To what extent do you feel that you were involved in the decision-making process for choosing treatment?	
	To what extent do you feel that your needs, wishes, preferences were considered by the doctor?	
	Did he/she advise you on possible changes in your lifestyle?	
	Currently, who is responsible for your regular monitoring, as part of your treatment?	
	• Of what specialty is this doctor?	
	How did you choose him/her/Have you been referred to others before?	
	How would you describe your relationship (your communication) with him/her?	
Are you satisfied with your doctor?		
Treatment	Do you experience any difficulties in accessing your doctor?	
	What do you think about your treatment?	
	How easy is it for you to follow the instructions for your medication?	
	What other instructions (apart from medication) do you need to follow?	
	How easy is it for you do you think it is to follow them?	
		What difficulties do you experience with your treatment (pharmaceutical and non-pharmaceutical)?

Continued

<u>Present (looking at «today»)</u>	Consequences	What do you think about your illness today? What impact do you think MS has on your life? • Family relationships • Professional life • Social relationships
	Support	What sources of support have you had so far? What kind of support do you currently receive? How satisfied are you? What organised support services do you think should be in place for MS patients? • Psychological support • Other types of support
	Health status	How would you describe your health today? Are there any other health problems that concern you? (either because of MS or not) Do you see doctors of other specialties or other health professionals for these problems?/ What kind of medical exams/test do you have? How is your cooperation with the doctor who treats your MS?
	Cost	How do you cover the costs of MS (doctor's visits, medicines) (i.e. do you receive an allowance)? What other expenses of any kind do you have related to the disease? How easy is it for you to meet the costs related to your illness?
<u>GENERAL</u>		How has the disease affected your life? What do you think could help you cope better with this experience? What should change in MS patient care services, considering your own experience?
<u>FUTURE (Looking at «tomorrow»)</u>		How do you see the future? What worries you most? What do you hope?

Table A2. Consolidated Criteria for Reporting Qualitative Research (COREQ): 32-item checklist.

No. item	Guide questions/description	Reported on page #
Domain 1: Research team and reflexivity		
<i>Personal characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	3
2. Credentials	What were the researcher's credentials? e.g. Ph.D., MD	3
3. Occupation	What was their occupation at the time of the study?	3
4. Gender	Was the researcher male or female?	3
5. Experience and training	What experience or training did the researcher have?	3
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	3
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	3

Continued

8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. bias, assumptions, reasons and interests in the research topic	n/a
Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	3, 4
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	2
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	2, 3
12. Sample size	How many participants were in the study?	3
13. Non-participation	How many people refused to participate or dropped out? Reasons?	n/a
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	3, 4
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	3, 4
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	3
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	3
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	3
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	3
20. Field notes	Were field notes made during and/or after the interview or focus group?	4
21. Duration	What was the duration of the interviews or focus group?	3
22. Data saturation	Was data saturation discussed?	4
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	n/a
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	4
25. Description of the coding tree	Did authors provide a description of the coding tree?	4, 5
26. Derivation of themes	Were themes identified in advance or derived from the data?	5
27. Software	What software, if applicable, was used to manage the data?	n/a
28. Participant checking	Did participants provide feedback on the findings?	n/a

Continued

<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	5 - 16
30. Data and findings consistent	Was there consistency between the data presented and the findings?	n/a
31. Clarity of major themes	Were major themes clearly presented in the findings?	5 - 16
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	5 - 16

Note: Developed from [Tong et al. \(2007\)](#).