Original Article

Understanding Palliative Care Needs in Multiple Sclerosis: Insights from a Qualitative Descriptive Study

Sara Arianmehr[1,2], Mahin Gheibizadeh[3], Neda Sayadi[3], Maryam Rassouli[4,5], Mehrnaz Moradi Kalboland[3], Nastaran Majdinasab[6]

[1]Student Research Committee, School of Nursing and Midwifery, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran, [2]Department of Anesthesiology, School of Allied Medical Sciences, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran, [3]Department of Nursing, Nursing Care Research Center in Chronic Diseases, School of Nursing and Midwifery, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran, [4]Cancer Research Center, Shahid Beheshti University of Medical Sciences, Tehran, Iran, [5]School of Nursing, College of Health Sciences, University of Nizwa, Nizwa, Sultanate of Oman, [6]Musculoskeletal Rehabilitation Research Center, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran

Abstract

Background: Given the variability in the provision of palliative care for patients with multiple sclerosis (MS) across diverse communities and cultural contexts, and considering the paramount importance of a patient-centered approach in needs assessment, this study aimed to identify the palliative care needs of individuals with MS. **Materials and Methods:** This qualitative descriptive study employed a directed content analysis approach on 2024. Data were collected through semistructured and in-depth 30-minute interviews with 14 patients diagnosed with MS in southern Iran. The interviews continued until data saturation was achieved. Concurrently with data collection, analysis was performed using the Elo-Kyngas method and MAXQDA 2022. The Guba and Lincoln criteria were utilized to ensure the validity and reliability of the data. **Results:** The analysis identified eight primary categories of needs that align with the National Consensus Project framework: structure and processes of care, physical, psychological and psychiatric, social, cultural, ethical and legal, spiritual, religious, and existential aspects, and end-of-life care. **Conclusions:** A thorough understanding of the palliative care needs of patients with MS can improve the responsiveness of the treatment team and empower caregivers to address these needs more effectively. Consequently, this leads to the delivery of more comprehensive palliative care services for these patients. While the palliative care needs of patients can be considered a multidimensional concept, determining the perceptions of family caregivers and healthcare providers regarding these needs is recommended to develop a more comprehensive approach in future research.

Keywords: *Health services needs and demand, multiple sclerosis, palliative care, qualitative research*

Introduction

Multiple sclerosis (MS) is a progressive and debilitating autoimmune disease that affects the central nervous system, characterized by the destruction of myelin.[1] According to official statistics from the World Health Organization (WHO) for 2025, over 1.8 million people have MS worldwide. In 2020, the global prevalence was 35.9 cases per 100,000 individuals. It is estimated that one new case of MS is diagnosed every 5 min worldwide.[2] A similar trend has been observed in the Middle East, where the prevalence of MS has been steadily increasing over the past few decades.[3] Numerous studies conducted in Iran have also indicated the rising incidence of this disease.[3,4] In 2019, the estimated prevalence of MS in Iran was approximately 16.5 cases per 100,000 men and 44.8 cases per 100,000 women.[5] The disease primarily affects young adults aged 20 to 40, with a higher incidence in women. MS is associated with a variety of physical and psychological challenges, including ataxia, visual impairments (such as blurred and double vision), fatigue, respiratory issues, urinary and fecal incontinence, sexual dysfunction, memory loss, and various mood, cognitive, and emotional disorders.[6-8] The progressive nature of MS significantly impacts patients' family life, economic stability, and social relationships, leading to a decline in quality of life (QoL), reduced work productivity, and, in some cases, frequent absenteeism, job loss, or the acceptance of new positions with lower income.[9,10] Consequently, this disease affects multiple aspects of patients' physical, mental, and social well-being, necessitating a comprehensive range of interventions in the form of palliative care.[11] According to

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Address for correspondence:
Dr. Mahin Gheibizadeh, Nursing Care Research Center in Chronic Diseases, School of Nursing and Midwifery, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran. E-mail: gheibizadeh-m@ajums.ac.ir

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the 2020 Palliative Care Atlas, patients with MS are among 20 groups that require palliative care services aimed at preventing and alleviating suffering through comprehensive assessments and treatments. In alignment with the WHO's Global Atlas of Palliative Care (2020), palliative care begins at diagnosis and is applicable throughout the disease course—not only in advanced stages.[12] This approach is recognized as a fundamental right for individuals affected by life-limiting and progressive diseases, as outlined in a resolution issued by the WHO.[13] A substantial body of research supports palliative care as a cost-effective strategy for managing symptoms and improving QoL in patients with MS.[13,14] The provision of specialized palliative care services has been shown to enhance symptom control, facilitate effective clinical pain management, reduce anxiety for both patients and their families, and ensure the delivery of high-quality care.[14] Despite the evidence demonstrating the effectiveness of palliative care, access to such services remains limited for many MS patients globally, particularly in low- and middle-income countries.[15]

In most studies, symptom management is identified as one of the most common unmet needs among MS patients.[16-18] Dadsetan *et al*. conducted a descriptive analytical study in 2017 to ascertain the palliative care needs of MS patients from the perspectives of nurses and patients in southeastern Iran.[19] The findings indicated that both nurses and patients recognized the palliative needs of MS patients across physical, social, spiritual, psychological, and economic dimensions. However, the results revealed a significant difference between the two groups in all dimensions of palliative needs.[19] Aranđelović *et al*. conducted a cross-sectional study in Serbia in 2024 aimed at identifying the palliative care needs of patients with MS.[20] Their findings revealed that 7.36% of participants expressed a need for palliative care, with the most significant needs related to physical symptoms, independence, and activity levels. The most commonly reported physical symptoms among individuals diagnosed with MS included weakness, bladder dysfunction, fatigue, and varying degrees of dependence. Additionally, concerns regarding sexual health, low mood, and anxiety were identified as significant challenges within the psychological category.[19]

Although previous studies have identified physical palliative care needs in MS patients, most relied on quantitative methods and did not explore patients' lived experiences in depth. Given the sociocultural diversity and the importance of understanding patients' own perspectives, this qualitative study aimed to provide a deeper, context-sensitive insight into the palliative care needs of individuals with MS in southwestern Iran. Previous studies on palliative care for patients with MS have primarily focused on identifying physical needs such as fatigue, muscle weakness, and bladder dysfunction. While there is general agreement on these aspects, most of the existing research has relied on quantitative methods and standardized instruments, which may not fully capture the lived experiences and nuanced needs of patients.

Palliative care is inherently multidimensional, encompassing psychological, social, spiritual, communicative, and economic domains. In many regions—particularly in low- and middle-income countries—these dimensions remain underexplored. Although some descriptive studies have been conducted in Iran, few have adopted a qualitative approach that directly engages patients in culturally specific contexts. This gap underscores the need for deeper, context-sensitive inquiry.

The present study addressed this need by employing a directed content analysis approach to explore the palliative care needs of MS patients in southwestern Iran from their own perspectives. Therefore, this qualitative study aimed to explore the palliative care needs of patients with MS from their own perspectives in southwestern Iran.

Materials and Methods

This qualitative descriptive study employed a directed content analysis approach on 2024. The conceptual framework of the study is based on the National Consensus Project (NCP) for Quality Palliative Care. The NCP outlines evidence-based processes and methodologies for improving and evaluating the quality of palliative care. It defines palliative care as an approach focused on symptom management, assessing and supporting the needs of caregivers, and coordinating care. The NCP aids individuals facing serious illnesses and the associated symptoms and stress, thereby enhancing their QoL. It considers palliative care across eight dimensions of care: physical, psychological, social, cultural, ethical/legal, spiritual, and end-of-life. These dimensions are relevant to patients with life-limiting and challenging-to-treat illnesses.[21] Rather than redefining its eight established domains, this study applied the NCP framework in a context-sensitive and flexible manner to explore how these dimensions are experienced, prioritized, and expressed by patients with MS in southwestern Iran. The NCP served as a comprehensive analytical guide, ensuring systematic coverage of physical, psychological, social, cultural, ethical/legal, spiritual, and end-of-life aspects of care. Importantly, the content within each domain was derived directly from participants' lived experiences, allowing for the identification of locally grounded expressions of palliative needs. For instance, while the "social" domain is broadly defined within the NCP, this study revealed specific concerns such as workplace exclusion, fear of losing familial roles, and the need for culturally embedded social support—elements that are often underrepresented in standardized assessments. By integrating a validated theoretical framework with experiential data, this study aimed to generate insights that reflect the real-world needs of MS patients and inform the development of tailored, culturally responsive palliative care models.

This qualitative study utilized a directed content analysis approach to identify the palliative care needs of patients with MS. Content analysis is defined as a process of organizing and synthesizing qualitative data based on identified themes and concepts. The objective of directed content analysis is to either validate or develop a theoretical framework.

The study included 14 patients who attended the neurology department, neurology clinic, and emergency department of Golestan Ahvaz Hospital, a referral center for patients with MS in southern Iran, as well as the MS Association office in Khuzestan province, Iran. Participants were selected regardless of disease stage, relapse frequency, or degree of functional limitation, in alignment with the WHO's definition of palliative care, which emphasizes early intervention from the point of diagnosis. The inclusion criteria—adults aged 18 and above with a confirmed MS diagnosis, awareness of their condition, ability to communicate, and willingness to share experiences—were determined to capture a broad spectrum of emerging palliative needs. This approach allowed the study to reflect the diverse challenges faced by individuals with MS, including those in early stages who may experience significant physical, psychological, or social distress, thereby supporting a holistic understanding of palliative care across the illness trajectory.

The data were collected through semistructured, individual, in-depth interviews. All interviews were conducted by a researcher from the MS Society and Golestan Hospital. The data collection period extended from February 2024 to July 2024, concluding when data saturation was achieved. Data saturation occurs when no new data are obtained from the interviews. The interviews began with open-ended questions, such as "What kind of care are you currently receiving?" and "What services and care do you require?" Participants were then encouraged to articulate any perceived deficiencies in the services they were receiving, as well as any unmet needs from their care providers. As the interviews progressed, probing questions like "Can you elaborate on that?" and "Can you provide an example?" were posed based on the participants' responses. The average duration of each interview was approximately 20–40 min. Participants were informed at the outset that they could interrupt the interview at any time if they felt fatigued, and that it would resume after a break. If a participant strayed from the main topic, follow-up questions and techniques were employed to guide them back to the primary focus of the interview. For instance, when a participant stated, "Sometimes I feel like no one understands how exhausted I am, even when I am not doing anything," the interviewer followed up with: "Can you give me an example of a situation where you felt this way?" This probing question encouraged the participant to elaborate on specific experiences, revealing deeper insights into the emotional and physical fatigue associated with MS and the perceived lack of empathy from care providers. At the conclusion of each session, participants were invited to share any points that had not been addressed. All interviews were recorded with the participants' consent and subsequently transcribed verbatim for analysis.[22]

The data analysis utilized the approach proposed by Elo and Kingas (2020). This method consists of three stages: preparation, organization, and reporting [Table 1]. The preparation stage includes the selection of an appropriate sampling strategy, the decision to analyze either overt or covert content, the conducting and implementation of interviews, and immersion in the data. The organization stage entails the creation of a hierarchical classification structure and the induction of main categories from the

Table 1: Qualitative data analysis process based on the method of Elo and Kingas (2020)

Preparation phase	Selecting the unit of analysis	After converting the interviews to text format, the explicit content (the interview transcripts) and the implicit content were analyzed, and semantic units were identified.
	Finding the logical connection of data with the overall topic	To maintain continuous and long-term engagement with the data, the interview text was read multiple times by the student to gain a comprehensive understanding.
Organization phase	Creating an analytical matrix	Care structure and process, the physical aspect of care, the psychological aspect of care, care of the dying patient, the social aspect of care, the cultural aspect of care, and the ethical–legal aspect of care were identified as the main categories in the nonimposed matrix.
	Extracting data from content based on categories	The main categories were formed based on conceptual and logical connections with other categories, and ultimately, the categories were defined based on the research framework.
	Grouping	The number of codes was reduced by merging similar codes based on their differences and similarities into broader codes.
	Classifying	The formed groups were categorized based on their differences and similarities (merging similar groups).
	Abstracting	The identified categories were placed within the existing main and initial categories in the analytical matrix.
Reporting phase	The sampling process, participant characteristics, data collection, data analysis, and each major category were reported in detail.	

initial codes (i.e. grouping, classifying, summarizing, and abstracting).[22] The objective of this stage is to reduce the number of categories by consolidating similar and dissimilar items at higher levels, thereby enhancing the description of phenomena, increasing understanding, and facilitating knowledge production. The final stage of the analysis process is the reporting stage, which involves documenting all steps of the guided content analysis and presenting the findings. The data were analyzed using MAXQDA software. Lincoln and Guba's criteria were utilized as standards for assessing data validity.[23] Ensuring the credibility of the data involved continuous and prolonged engagement, ongoing observation, peer review, researcher interaction, and participant review of interview transcripts. To promote transferability, the researcher aimed to include participants with maximum variation. To enhance confirmability, the research team enlisted the assistance of four external, expert qualitative research observers, who meticulously verified the data analysis process. The dependability of the research was ensured through careful monitoring of the data collection and analysis processes by the research team. To this end, coding and categorization of codes were conducted by two researchers (MG and SA) and ultimately validated by other team members.

Ethical considerations

The present study was approved by the Ethics Committee of Ahvaz Jundishapur University of Medical Sciences (IR.AJUMS.REC.1402.476). Participation was voluntary, and written informed consent was obtained from all participants. Confidentiality and data integrity were strictly upheld. During interviews and ethical principles were maintained through procedural safeguards and interpersonal sensitivity. Given the emotional nature of end-of-life care, the interviewer—trained in empathy, neutrality, and cultural awareness—introduced sensitive topics gradually and in a nondirective manner. Questions related to end-of-life needs were introduced gradually and framed in a non-directive manner—for example, by asking: "Are there any aspects of care you feel are missing or difficult to talk about?"—rather than using clinical or emotionally charged language. Participants were reminded of their right to pause or skip any question, and verbal and non-verbal cues were monitored for signs of distress. If emotional discomfort was observed, the interview was paused and supportive options, including withdrawal from the study, were offered. These measures reflected a strong commitment to psychological safety and participant autonomy.

Results

In this study, a total of 14 patients were interviewed, and the demographic characteristics of these individuals are presented in Table 2. The analysis of the interview data yielded 179 initial codes and 22 subcategories, which corresponded with the National Consensus Project Framework across eight dimensions: "Structure and Process of Care," "Physical Aspects of Care," "Psychological Aspects of Care," "Social Aspects of Care," "Cultural Aspects of Care," "Ethical and Legal Aspects of Care," "Spiritual, Religious, and Existential Aspects of Care," and "Care of Patients in End-of-Life Stages" [Table 3].

The present study identified eight primary categories.

Category 1: Structure and processes of care

This dimension outlines the components of palliative care assessment, care plans, and the specific systems and processes involved in delivering palliative care. It consists of four subcategories: the need for developing and allocating community-based specialized services, the need for facilitating equitable access to services, the need for developing diagnostic and screening services, and the need for providing effective educational services.

Need for developing and allocating community-based specialized services

The need for community-based service development has been identified by research participants as a priority, with the availability of specialized services in the community

Table 2: Characteristics of participants in the study

Participant ID	Age (years)	Gender	Occupation	Education level	Marital status	Interview duration (min)
1	32	Female	Preschool teacher	Master's degree	Married	38
2	30	Female	Employee	Bachelor's degree	Married	40
3	53	Male	Taxi driver	High school diploma	Married	25
4	38	Female	Housewife	High school diploma	Married	40
5	49	Female	Housewife	Elementary school	Married	29
6	44	Female	Housewife	High school diploma	Married	40
7	42	Female	Housewife	Illiterate	Married	35
8	33	Female	Teacher	Bachelor's degree	Single	25
9	37	Male	Employee	Bachelor's degree	Single	40
10	56	Female	Housewife	Illiterate	Married	40
11	29	Female	Housewife	Bachelor's degree	Married	41
12	46	Female	Housewife	High school diploma	Married	40
13	27	Male	Unemployed	High school diploma	Married	20
14	45	Male	Shop owner	Bachelor's degree	Married	32

Table 3: Themes, categories, and subcategories resulting from the content analysis of interview data

Themes	Categories/Subcategories
Structure and processes of care	Need for development and allocation of community-based specialized services
	Need for home care services
	Need for telehealth services
	Need for the development of specialized outpatient services
	Need for equitable access to services
	Need for development of diagnostic and screening services
	Need for effective educational services
Physical aspects of care	Need for management of progressive physical symptoms
	Need for controlling secondary complications arising from treatment
Psychological and psychiatric aspects of care	Need for management of psychological and emotional symptoms
	Need for the development of mental health services
	Uncertainty about the prognosis of the disease
	Deficiencies in mental health services
Social aspects of care	Need for affordable comprehensive services
	Need for home environment improvement
	Need for support from social institutions
	Need for reconstruction and adjustment of social roles and interactions
	Disruption in the patient's social roles
	Social isolation
Cultural aspects of care	Need for social stigma reduction
	Need for correction of the patient's cultural beliefs
Ethical and legal aspects of care	Need for allocation of time and responsiveness by the therapist
	Need for receiving attention and respect from the therapist
	Need for companionship at the bedside
Spiritual, religious, and existential aspects of care	Spiritual growth
	Need for connection with God
	Belief in divine testing
Care of the patient nearing the end of life	Need for controlling physical symptoms in the final stage of life
	Need for spiritual and emotional support in the final stages of life

considered essential for ensuring accessible care. Home care, recognized as an effective model for community-based care, plays a crucial role in delivering comprehensive services to patients with chronic diseases. Individuals diagnosed with MS face significant challenges in performing daily activities, highlighting the importance of regular home visits by nurses. This emphasizes the necessity for the development of home care services and an increase in the number of trained nurses to provide palliative care within the patient's home environment, particularly for those experiencing prolonged hospitalizations. One patient expressed the following sentiment: "*I wish I could call somewhere when I am sick and have a nurse come to my house to administer my IV and medications*" (P 5).

Conversely, patients expressed a preference for remote services, such as telehealth, to avoid in-person visits due to various reasons, including weakness or complications. This choice was influenced by the challenging circumstances they faced. One patient articulated this sentiment, stating: "*I wish I could have an online consultation when I am unable to visit the doctor's office due to severe weakness*" (P 6).

A significant concern expressed by patients was the necessity of visiting hospitals and specialized centers to receive even basic services. As there are numerous healthcare centers located near patients' residences, many choose to utilize these local facilities instead of traveling to distant hospitals. This situation underscores the need for a tiered approach to palliative care services. One patient remarked: "*It is very challenging that we have to come to the hospital to obtain medication. I wish they would provide medications at all local clinics*" (P 8).

Need for facilitating equitable access to services

Fair distribution of health resources and services is a significant concern for policymakers, as it plays a crucial role in managing and allocating resources within the healthcare system. The participants in this research expressed a need for improved access to equitable services. In this context, one patient remarked: "*The fact that we have to travel from the county to Ahvaz, and that there are no specialist doctors or these medications available in small towns is truly unfair*" (P 7).

Another patient expressed that: "*It upsets me that I have to pay a significant amount for physiotherapy sessions, while these services are provided free of charge to patients in Ahvaz*" (P 6).

Need for developing diagnostic and screening services

According to the participants' statements, early diagnosis of MS can significantly slow its progression and prevent disabilities associated with the disease. As one patient articulated: "*If my illness had been diagnosed sooner and I had undergone brain imaging, I might not have experienced the severity of symptoms I did. If my illness had been diagnosed sooner and a brain MRI had been prescribed for me, I would not have felt so unwell*" (P 8).

Additionally, another participant remarked: "*It took me two years to receive a diagnosis. I consulted with various medical professionals repeatedly, and each one attributed my walking difficulties to a different condition, specifically my spine*" (P 7).

Need for providing effective educational services

The need for effective educational services emerged as a recurring theme among the patients. Many reported a lack of information from healthcare professionals regarding the nature of their disease, treatment options, and care procedures. One patient expressed this concern, stating: "*Neither the doctor nor the nurse explained what I should do if I forget a dose of medication" (P 5).*

Another patient remarked: *"The doctor did not provide any explanation or education about my disease and treatment process"* (P 14).

Category 2: Physical aspects of care

In this context, the planning of care and treatment for physical symptoms has been clearly defined, emphasizing comprehensive and essential patient care. This category includes two subcategories: the need for managing progressive physical symptoms and the need for controlling secondary side effects of treatment.

Need for managing progressive physical symptoms

The necessity for managing progressive physical symptoms has been clearly identified. An assessment of palliative care needs related to physical health has revealed that patients with MS often experience several symptoms simultaneously. The management of symptoms such as weakness, fatigue, imbalance, difficulty with movement, and reliance on assistance for daily activities emerged as significant needs for patients in this study. One patient expressed their experience with these symptoms, stating: "*I am unable to ascend stairs, stand upright, or walk independently. I am undergoing physiotherapy to prevent total paralysis*" (P 10).

Another patient shared their struggles with physical limitations, saying: "*I am experiencing profound fatigue and a complete lack of energy, to the extent that I cannot perform any activities. I suffer from body aches and depend on my children for all my tasks*" (P 7).

Need for controlling secondary side effects of treatment

A significant number of patients reported using a wide range of immunosuppressant drugs and other categories of medication, which led to the occurrence of secondary treatment side effects. This highlights the need for more specialized assessments and care to improve their QoL. *"I frequently experience urinary tract infections. The physician's response indicated that the use of steroids can weaken immune system function, thereby increasing the risk of infection"* (P 7).

"*Due to my prolonged use of steroids, I have developed diabetes and severe osteoporosis*" (P 10).

Category 3: Psychological and psychiatric aspects of care

This category includes the ongoing assessment process and the consideration of psychological and psychiatric aspects of MS care. It consists of two subcategories: the need to manage psychological and emotional symptoms and the need to develop mental health services.

Need to manage psychological and emotional symptoms

Participants expressed a need for improved psychological care, particularly in managing anxiety, depression, and psychological distress associated with MS. Patients emphasized the importance of ongoing support from their families, with some reporting feelings of burden or shame due to their dependence on others, especially during periods of significant physical weakness. "*I feel overwhelmed by my own burden and the challenges I pose to my family. I find myself contemplating the end of my life. I am exhausted, and I am tired of this life filled with misfortune and weakness*" (P 7).

"*My daughter is responsible for performing my domestic duties and bathing me. I feel so ashamed*" (P 10).

Need for developing mental health services

The necessity for the development of mental health services has been recognized, encompassing two subcategories: uncertainty about the prognosis of the disease and deficiencies in mental health services. Individuals diagnosed with MS often experience anxiety, depression, confusion about the future trajectory of their illness, and a sense of despair, all of which can negatively impact their QoL. Providing psychological counseling and enhancing mental health services have been demonstrated to improve patients' psychological well-being, thereby alleviating feelings of loneliness and isolation. "*I am uncertain about the future course of my illness. Is this disease fatal, or will I simply become paralyzed?*" (P 14).

"*I consistently entertain the idea that I am destined to succumb to paralysis at some point, which creates a reluctance to seek treatment*" (P 13).

Deficiencies in mental health services were also highlighted by patients. One participant stated: "*Following my diagnosis of MS, there was a lack of support to help me cope with the emotional distress. Unfortunately, there was a widespread indifference to my well-being and the coping mechanisms available to me*" (P 3).

Category 4: Social aspects of care

This category of palliative care involves assessing and addressing the patient's social support needs, which can be categorized into four distinct areas: need for affordable comprehensive services, need for improvement of the home environment, need for support from social institutions, and need for the reconstruction and adaptation of social roles and interactions.

Need for affordable comprehensive services

Patients experiencing economic difficulties and an inability to afford medical expenses, including medications, diagnostic tests, and medical equipment, have encountered a heightened demand for financial assistance from the community and charitable organizations. "*I often delay many necessary rehabilitation measures because we cannot afford the costs*" (P 7).

"*Not all of our medications are free. When the doctor increases the dosage or prescribes foreign medications, we must purchase them from a private pharmacy*" (P 5).

"*The MS Association can refer us to free hydrotherapy, physiotherapy, and occupational therapy centers. They should increase their financial support*" (P 4).

Need for improvement of the home environment

A number of participants agreed that the residential environment is not conducive to the well-being of individuals diagnosed with MS. The presence of motor impairments, balance issues, fatigue, weakness, and malaise necessitate the implementation of measures to modify the living environment, thereby facilitating easier access to spaces and amenities within the home. *"Due to my inability to stand and cook, my stove was relocated to the floor, allowing me to prepare meals independently"* (P 7).

"*When I need to use the bathroom, I am concerned about losing my balance after getting off the toilet*" (P 3).

Need for support from social institutions

Participants stressed the need for support from social institutions. Patients sought financial help from families and society. Also, some proposed developing social work services to address economic and livelihood challenges. The need for social support and group connections is crucial. It can enhance patients' QoL. "*If the Welfare Organization would help me to have a wheelchair, I could move around the house without help*" (P 7).

Need for reconstruction and adjustment of social roles and interactions

We need to rebuild social roles for two reasons: role disruption and social isolation. This study found that patients often had reduced work capacity due to the disease. This led to job loss, reduced hours, and frequent absences. "*I am an accountant. Whenever I felt unwell and knew I could not type or do calculations, I would take sick leave and not go to work*" (P 2).

Another patient, a teacher, said: "*I fear my superiors will find out about my condition and fire me. Who would want a teacher with MS?*" (P 1).

Patients reported feelings of loneliness and abandonment following their diagnosis. Social isolation is a consequence of the disease. "*Before my illness, I often engaged with friends and neighbors, but my interactions with them have decreased significantly*" (P 4).

"*Since my illness, I rarely see my friends and neighbors. I no longer attend social gatherings. I do not enjoy being physically held and taken away from social gatherings*" (P 10).

Category 5: Cultural aspects of care

This category covers the cultural factors that affect palliative care, which are of two types. The first is the need for social stigma reduction. It aims to reduce societal prejudices and misconceptions about some health issues. The second subcategory is the need to address the patient's cultural beliefs. It is about addressing misconceptions and providing accurate cultural information to patients.

The need for social stigma reduction

Participants noted a lack of public awareness about MS. Many patients felt the public did not understand the disease. This created a social distance between patients and society. Participants tried to hide their illness due to stigma. "*I did not want anyone to know I had MS. I was afraid of how others would treat me. Would they pity me or be afraid of me? Their physical appearance was a source of distress for me*" (P 10).

"*At first, I felt significant trepidation because of the gravity of the condition. Awareness of it is very low*" (P 5).

"*It was as if I had AIDS. My colleagues' views of me changed. They were afraid of me. They were afraid of contracting MS if they came near me*" (P 2).

Need to address the patient's cultural beliefs

The participants believed that healthcare should respect the local culture and customs. It must respect patients' cultural and religious beliefs. One patient said: "*I am certain that my recovery will improve if I do not get exposed to my mother-in-law. She put me under great psychological pressure. It caused my MS*" (P 6).

Category 6: Ethical and legal aspects of care

This category covers advanced care planning and decision-making in sensitive cases. It includes ethical and legal issues, with a focus on supporting patient autonomy. This aspect has three subcategories: the need for the therapist's time and responsiveness, the need for attention and respect from the therapist, and the need for a bedside companion.

Need for the therapist's time and responsiveness

The therapist's responsiveness and a set time were seen as crucial. Participants stressed the need for ethical care. This means respecting patients' time, answering their questions, and meeting their needs. It is a key part of the patients' rights charter on medical care. Many patients felt that doctors did not spend enough time on exams and care. They also felt that doctors did not answer their questions. "*The doctor does not even take the time to answer my questions. The clinic has too many patients. They see two patients at once*" (P 5).

"In the hospital, the doctor only comes to see you once. He does not explain the patient's condition or provide education" (P 3).

Need for attention and respect from the therapist

It is vital for healthcare professionals to be respectful and considerate. This is a key concern for these patients. "*Despite my illness, I have not received the respect I deserve from the medical staff. I have a first name and a last name, but they call me as MS patient*" (P 3).

"*The medical staff disregard my individuality. For instance, the physician conducted a quick examination of me. He dismissed my concerns without hesitation. I took this as a sign of disrespect. Even if I am going to die, tell me*" (P 10).

Need for a companion at the bedside

Many patients wanted a companion at their bedside. They felt that others ignored their wishes. For instance, one patient said: "*They will not let my daughter stay with me. Despite repeated requests, the nurse was not dispatched. I lack the physical strength to move my foot*" (P 10).

Another patient said: "*They have been removing companions from the ward. There is no one to provide water*" (P 3).

Category 7: Spiritual, religious, and existential aspects of care

The care had positive effects. It led to personal and spiritual growth. People shared their experiences through positive statements. These positive aspects fell into three subcategories: spiritual growth, need for connection with God, and belief in divine testing.

Spiritual growth

The patients' encounter with this stressful illness event led to spiritual growth. Spiritual growth is a complex idea. It means a personal connection with a higher power. It may lead to a deeper connection with God, a constant conversation with God and hope in Him, a changed perspective on life, and more reflection on life's philosophy. "*I reached a point where I said: 'God considered me more valuable and gave me this illness to bring me closer to Him. I have got endless appreciation*'" (P 12).

"*With this illness, my perspective on life underwent a significant shift. It was as if all trivial matters became of negligible importance to me*" (P 10).

"*This illness has been instrumental in fostering a deeper appreciation for life. To appreciate the health that God has bestowed upon me*" (P 9).

Need for connection with god

Several patients expressed a need to connect with the divine. During their illness, patients wanted to connect with God. They believed this deep bond helped them cope with the disease. One patient echoed this, saying: "*I communicate with God. I make many vows. This practice provides me with solace"* (P 7).

Another patient said *"that they find solace in prayer and sending blessings in tough times" (P 10).*

Belief in divine testing

Some participants emphasized that contracting MS was a form of divine testing. This view is that, when God decrees something, one must accept it completely and submit to His will. One patient said: "*I wonder if this ordeal is a divine test*" (P 10).

Another believed their illness was due to past sins, and they were paying the price for their past actions (P 14).

Category 8: Care of patient nearing the end of life

This section is devoted to an examination of the symptoms and conditions that are most prevalent in the final days and weeks of life. These symptoms and conditions fall into two subcategories: the need for controlling physical symptoms in the final stage of life, and the need for spiritual and emotional support in the final stages.

Need for controlling physical symptoms in the final stage of life

Patients require palliative care in the final stages of their illness. Patients stressed the importance of palliative care that focuses on symptom management. They expected the treatment team to meet their needs during these vulnerable times.

One patient wanted to avoid pain in their final days (P 10). Another patient voiced concern about bedsores and stressed the need to manage pain and prevent complications (P 7).

Need for spiritual and emotional support in the final stages

A recurring theme among the participants was the need

for support in the final stages of life. They stressed a need for spiritual and emotional support. They wanted others to respect their personal preferences and wishes. Additionally, they sought clarity about their condition. Many patients wanted to spend their final moments in a peaceful, home-like place. Choosing a suitable place for the end of life, and providing support, became a major concern. "*I do not want to die in a hospital. I want to die in my own home, in my own bed*" (P 6).

Another patient articulated a desire to engage in discussions about death: "*I no longer fear it. I am concerned about how my children will cope with my death*" (P 13).

Some preferred to stop invasive treatments and wished for a peaceful death. "*Why should I endure more suffering when there is no hope of recovery*?" (P 14).

Discussion

This study aimed to determine the palliative care needs of people with MS. The findings showed that individuals with MS have diverse palliative care needs. While it is true that many core palliative care needs—such as pain management, emotional support, and assistance with daily functioning—are shared across chronic conditions, patients with MS face distinct challenges that warrant tailored approaches. The unpredictable disease trajectory, fluctuating symptoms, cognitive impairments, and progressive physical limitations contribute to a unique constellation of psychosocial and existential concerns.[11] Moreover, MS patients often experience stigma, uncertainty in decision-making, and a gradual loss of autonomy, which intensify their need for specialized communication, psychological support, and anticipatory guidance.[24] Therefore, while the foundational principles of palliative care remain consistent, the context-specific manifestations in MS necessitate nuanced and individualized interventions.

These needs span various categories. These categories include: care structure and process, physical care, psychological care, social care, cultural care, ethical and legal care, spiritual and existential care, and end-of-life care. These findings are consistent with the NCP framework.

About care process and structure, participants noted a lack of care infrastructure. They called for better care processes. This includes community-based, specialized, and diagnostic services, as well as education. The participants stressed the need for community-based specialized services. These include home care, remote care, and tiered services. This finding supports earlier studies. They stressed the importance of home and outpatient palliative care for MS patients.[25] The study stressed the need for better infrastructure and more trained nurses. They must be skilled in palliative and home care. This finding suggests a need for major reforms in MS healthcare. Iran lacks an adequate number of end-of-life care centers. This is despite a rising demand for these services. They are needed due to chronic, life-threatening diseases. The lack of treatment centers is due to several key factors. They include, but are not limited to, inadequate infrastructure, a shortage of specialists, no care plans, no guidelines, no policies, cultural differences, and financial constraints.[26]

This highlights the need for better training for caregivers. We also need to improve the care system. It must provide more complete, multi-faceted care. Those with long-term neurological conditions, like MS, ALS, and Parkinson's, often face many issues. They have physical symptoms, psychosocial challenges, and various spiritual and emotional needs.[27]

A similar study found that unmet needs were common among patients. These unmet needs were reported in many areas of life. They include family and social support, daily activities, leisure, work, and healthcare. These individuals faced challenges in accessing healthcare. They had to travel far to see specialists, endure long waiting times, and deal with poor transport. A later survey found patients dissatisfied with several issues. These included: their diagnoses, care quality, and complications. Also, a lack of support, poor info, and bad service coordination.[28]

Our findings revealed that MS patients face many complex physical issues. They have a direct impact on their daily lives. A top concern for palliative care in this patient group is managing chronic symptoms.[27,29,30] Also, pain is more common than estimated. This is in agreement with the findings of the studies by Kluger *et al*.[31] and Wilder.[15]

The present study, like many before it, shows the challenges and needs of these patients. A study in this area found that these patients expected their doctor to provide support when delivering bad news. They wanted others to treat them as humans, not as "patients".[25,32] Moreover, improving patients' understanding of MS helps their mental health. It does this by increasing awareness and improving disease management.[25] A study found that a palliative care team can reduce rejection, anxiety, depression, and isolation in MS patients.[27] Moreover, MS patients have a growing need for emotional support.[33] Like many chronic illnesses, MS can cause guilt, sorrow, worry, and despair.[33,34]

This study shows that MS patients face social and economic challenges. These challenges reduce their QoL and mental well-being. These patients often face job loss, money problems, and cannot pay for rehabilitation. A study indicated that reduced mobility leads to MS patients receiving less social support. Researchers found that a lack of social support lowers self-esteem. It also increases feelings of futility and helplessness.[35,36]

In this study, emotional support from family and friends was considered the most important factor of social support for patients because the presence of supportive friends and family facilitates access to the healthcare system and

promotes health.[28,37] Nurses and social workers noted that family and friends of MS patients need support. They need counseling about the disease and its effects. They also need palliative care at home during the disease's early stages. The financial challenges that MS patients face, often due to unemployment or early retirement, highlight a major cause of these issues. These financial constraints can cause dependence, debt, and poor child care.[27,37,38]

On the ethics of care, participants stressed that therapists must be responsive and respectful. They also valued having a companion at the bedside. The findings of Prasko *et al*.[34] indicated dissatisfaction with the quality of interaction between doctors and patients. MS patients want more time to talk to doctors. They want to receive bad news in a suitable manner. They want more empathy and compassion. Furthermore, they want others to listen to them with greater attention. They also want their doctors to help interpret the information they received. They want more info about the disease, its progression, and its treatments. Furthermore, they are also interested in available services.[34] Aranđelović *et al*.[19] noted that healthcare professionals involved in the care of patients with MS should provide them with empathetic support and information so that they can more easily cope with the life changes caused by the disease, as well as its consequences.

Dadsetan *et al*. compared palliative care needs from MS patients and neurological ward nurses.[20] Both groups stressed palliative care's physical category the most. Then, they ranked the social, spiritual, psychological, and economic categories. However, patients placed a higher priority on their needs in all categories compared to nurses. The study's findings stress that all MS patients need palliative care. They must receive care in all areas. It is vital to have care plans tailored to each patient's needs.[19]

Spirituality and religion are important in coping with illness. This study's findings are in agreement with those of other studies[39,40] that highlight the importance of spiritual and religious support for MS patients. Previous research shows that spiritual support can reduce anxiety. It can also increase peace in patients with chronic illnesses. The spiritual dimension has a significant impact on the health of chronic disease patients. It can improve their mental and physical health. Those with strong religious beliefs rely on faith and spiritual support. This helps them cope better with the stresses of illness.[40-42]

Finally, patients mentioned end-of-life needs. Most patients were willing to discuss end-of-life issues, given the progression of their disease. However, satisfaction with the level of communication on these topics was relatively low, which is in agreement with the findings of Strupp *et al*.[27] Discussion of death and dying is of critical importance, as, contrary to the popular belief that MS is not a fatal disease, mortality in patients with MS has increased significantly with a life expectancy reduction of 7–14 years.[43] Suicide rates in patients with MS are increasing, with depression being a major risk factor for suicidal thoughts, occurring in more than 25–30% of patients with MS.[28,44] These numbers reflect the amount of suffering that MS patients endure and indicate the necessity to improve their care options.[27]

Palliative care for patients with chronic illnesses, such as MS, is now essential in Iran. Initiatives are underway in major cities, such as Isfahan and Tehran. However, the community's approach to addressing the needs of MS patients and providing palliative care services, whether at home or remotely, is inadequate. This study identified that MS patients have a wide range of palliative care needs that are not adequately met by the current healthcare system. Addressing these complex needs requires a concerted effort from healthcare and treatment systems. A comprehensive understanding of the intricacies involved in palliative care for MS patients is crucial in facilitating the provision of customized services by caregivers. Caregivers, in particular, play a vital role in enhancing self-care and coping mechanisms among individuals living with MS. The findings emphasize the need for a comprehensive management approach to address the care needs of MS patients, aiming to improve their QoL and treatment outcomes.[25,38,45] This review is a pioneering effort in Iran, as it is the first to systematically examine palliative care needs from the patients' perspective. This comprehensive review provides a foundation for the development of patient-centered, multifaceted palliative care service packages. The scope of this research was limited to exploring the perceptions of healthcare providers regarding palliative care needs. While their insights are valuable, the exclusion of other stakeholders, such as family caregivers and patients themselves, may have led to an incomplete understanding of the multidimensional nature of these needs. Future research could benefit from adopting a more inclusive approach by involving a wider range of participants. Additionally, the study may be subject to biases inherent in qualitative data collection, including potential variations in responses due to differences in individual experiences or perceptions. Efforts to triangulate findings across diverse methods and perspectives would help address these limitations.

Conclusion

This study, through a comprehensive review of palliative care needs in MS patients, emphasizes the importance of a multifaceted and holistic approach to care. The findings indicate that the needs of these patients extend beyond the physical and psychological categories to encompass social, spiritual, cultural, ethical, legal, and end-of-life care structures and processes. Consequently, it is proposed that palliative care programs for MS patients be designed using a holistic approach based on NCP framework, addressing their specific needs in these dimensions. This approach is expected to enhance the QoL of these patients and alleviate the burden of the disease. The initial step in designing such a program is to understand the palliative care needs of MS patients.

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Conflicts of interest

Nothing to declare.

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