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Accessing palliative care for multiple sclerosis: A qualitative study of a neglected neurological disease

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A B S T R A C T

Background: Despite the global consensus on the importance of palliative care for patients with multiple sclerosis (MS), many patients in developing countries do not receive palliative care. Improving access to palliative care for MS requires a contextual understanding of how palliative care is perceived by patients and health professionals, the existing care pathways, and barriers to the provision of palliative care.

Objective: This study aims to examine and contrast the perceptions of MS patients, neurologists, and palliative care physicians towards providing palliative care for patients with MS in Malaysia.

Methods: 12 MS patients, 5 neurologists, and 5 palliative care physicians participated in this qualitative study. Each participant took part in a semi-structured interview. The interviews were transcribed verbatim, and analysed using an iterative thematic analysis approach.

Results: Patients and neurologists mostly associated palliative care with the end-of-life and struggled to understand the need for palliative care in MS. Another barrier was the lack of understanding about the palliative care needs of MS patients. Palliative care physicians also identified the scarcity of resources and their lack of experience with MS as barriers. The current referral-based care pathway itself was found to be a barrier to the provision of palliative care.

Conclusions: MS patients in Malaysia face several barriers in accessing palliative care. Overcoming these barriers will require improving the shared understanding of palliative care and its role in MS. The existing care pathway also needs to be reformed to ensure that it improves access to palliative care for MS patients.

1. Introduction

Multiple sclerosis (MS), an autoimmune demyelinating neurological disease is a major cause of neurological disability worldwide (Lublin and Reingold, 1996). Around the world, however, MS is a neglected neurological condition with many developing countries having little to no information on its epidemiological burden, hampering efforts to provide care for the MS population (Cheong et al., 2018b). One key area is palliative care.

MS patients are known to have complex palliative care needs and often experience a level of suffering comparable to patients with metastatic diseases (Higginson et al., 2006; Golla et al., 2012; Edmonds et al., 2007; Galushko et al., 2014; Strupp et al., 2012). On a global level, it is widely acknowledged that palliative care plays an important role in the care of MS (Global Atlas of Palliative Care, 2014). A recent review of palliative care research, however, reported that palliative care research in the Asia Pacific region is focused on cancer (with MS going virtually unmentioned) and suggests that a similar focus exists within palliative care practice (Cheong et al., 2018a).

This raises two questions: Are MS patients in the region recognized as being in need of palliative care, and why are they receiving (or not receiving) that care. Answering these questions requires an understanding of the health care systems as well as the professional and patient factors involved. Much of the literature on palliative care needs and the delivery of palliative care in MS, however, comes from countries with high prevalence of MS and well-developed palliative care services which may not be relevant to developing countries with different healthcare systems, practices, and cultures (Higginson et al., 2006,2009,2011; Golla et al., 2012,2014,2015; Galushko et al., 2014; Strupp et al., 2012,2014,2016; Edmonds et al., 2010; Buecken et al., 2012; Browne et al., 2014; Lynch et al., 2013; Knies et al., 2015).

To explore these issues, we use Malaysia as a case study. Malaysia is estimated to have a low prevalence of MS and a moderate level of palliative care service development (Lynch et al., 2013). MS patients rarely come into contact with palliative care. It is notable that the Malaysian Clinical Practice Guidelines for the management of multiple sclerosis had no mention of “palliative care” while a report in 2012 estimated that there were no MS patients in need of palliative care, a finding that has been disputed (Management of Multiple Sclerosis, 2015, Sekhar et al., 2016; Cheong and Reidpath, 2017).

The successful delivery of palliative care services to MS patients in Malaysia requires an understanding of its healthcare system and the

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underlying socioeconomic factors. It is also necessary to understand the local perceptions of palliative care, as well as the existing care pathways for accessing palliative care (Stjernsward et al., 2007; Kaasa et al., 2007). Unfortunately, relatively little is known about this.

Because so little is actually known about MS in Malaysia, and in the absence of an adequate surveillance system, a multidimensional, qualitative approach studying local MS patients, neurologists, and palliative care physicians was used to investigate the issues surrounding palliative care in MS.

1.1. Aims and objectives

This study aims to examine and contrast the perception of MS patients, neurologists, and palliative care physicians towards providing palliative care for patients with multiple sclerosis.

2. Methods

2.1. Sample and data collection

Participants from the MS patient group were identified with assistance from the MS Society of Malaysia and invited to participate. Neurologist and palliative care physician participants were identified through the Malaysian National Specialist Registry. In total, 12 patients, five neurologists and five palliative care physicians consented to participate in the study.

All the participants took part in a face-to-face, semi-structured interview. The length of the interviews were guided by the participants. Each interview was carried out using an interview topic guide but allowed for participants and the researcher to explore certain subjects in varying length and detail. The topics included: (1) the referral process and provision of palliative care to patients, (2) the perception of palliative care, (3) the need for palliative care in MS, (4) the barriers to providing MS patients with palliative care, and (5) improvements needed to improve access to palliative care. The interviews were audio-recorded and transcribed verbatim.

This study received ethical approval from the Monash University Human Research Ethics Committee (Project ID: 15040).

2.2. Analysis

An iterative thematic analysis approach was employed in this study (Braun and Clarke, 2006). A critical realist paradigm was adopted which assumes that there is an independent reality and each individual's interpretation of that reality is influenced by their experiences, culture, language, and context (Braun and Clarke, 2013).

All de-identified transcripts of the interviews were coded by the lead author (WLC). Throughout the coding process, implicit views were taken into consideration and analytical memos were made to complement the process. The codes as well as the raw data were multi-professionally discussed between the researchers (WLC, NW, DM, DDR). Constant comparative techniques were employed throughout the entire coding process for the development of categories and themes that described the participants' perspectives, attitudes, and experiences of palliative care and multiple sclerosis.

3. Results

3.1. Conceptual model of the provision of palliative care to MS patients

The participants provided insights into how an MS patient receive palliative care. This process allowed the researchers to construct a conceptual model of the provision of palliative care to MS patients (see Fig. 1).

This model highlights the interactions necessary for the successful delivery of palliative care. Specifically, before a patient receives treatment from a palliative care physician, a neurologist must first make a referral, a palliative care physician must accept the referral, and the patient must accept being referred for palliative care. This conceptual model allowed the researchers to explore and identify through interviews with the study participants the barriers to palliative care for MS patients and situate the barriers explicitly within the model.

3.2. Themes developed

The coding and subsequent analysis of the findings of this study led to the development of 4 themes: '**Understanding of Palliative Care**, '**The Need for Palliative Care in MS**', '**Barriers to Palliative Care**', and '**Improving Access**'.

3.3. Theme: understanding of palliative care

Patients and neurologists largely associated palliative care with the end-of-life. They perceived it as care that is provided to patients that were at the end-of-life, had no further treatment options available, or were suffering immensely. As a result, they did not regard palliative care as necessary or relevant for MS patients. Referrals to palliative care were perceived negatively. Referring a patient to palliative care was seen by some neurologists as giving up on the patient. Similarly, the patients perceived being referred to palliative care as an indication that they were at the end-of-life.

> I would still be quite worried about someone talking to me about palliative care. I guess a part of it is that at this stage, I'm really just focused on living and being positive and all that, and I suppose palliative care sends the opposite message to me. (PT12)

Both patients and neurologists expressed uncertainty about the role of palliative care. When asked to speculate, however, patients and neurologists described it as providing symptomatic relief, especially towards the end of life, and achieving a good death. The limited role of palliative care as defined by the patients and neurologists stood in contrast to how palliative care physicians perceived the role of palliative care, which is to provide relief from physical, mental, emotional or spiritual suffering.

3.4. Theme: the need for palliative care in MS

Each group perceived the need for palliative care in MS differently. Both the patients and neurologists struggled to see the need for palliative care in MS. One reason for this was the uncertainty of disease progression and symptoms experienced by MS patients. This uncertainty led some patients to hope that they would avoid any disabilities in the future and therefore, have no need for palliative care. The neurologists also struggled to determine which patients required palliative care and when they should be referred.

> For MS, it is a very different story. What kind of disabilities do you expect the patient to develop is also a guessing game… So it is hard for us to consider when patients should be referred to palliative care. (NEU04)

Notably, patients and neurologists focused on symptoms and stage of illness to decide if palliative care was needed. As such, some neurologists struggled to identify the need for palliative care in cases where the patient's symptoms were already being managed adequately.

> In terms of what is it that they can offer, I'm really not sure… I already manage most of the symptomatic needs of the patient, for example, with regards to pain, spasticity, constipation and all that. (NEU04)

Palliative care physicians, on the other hand, viewed the need for palliative care more broadly, taking into account the patient's symptoms as well as their quality of life, independence, and their decision

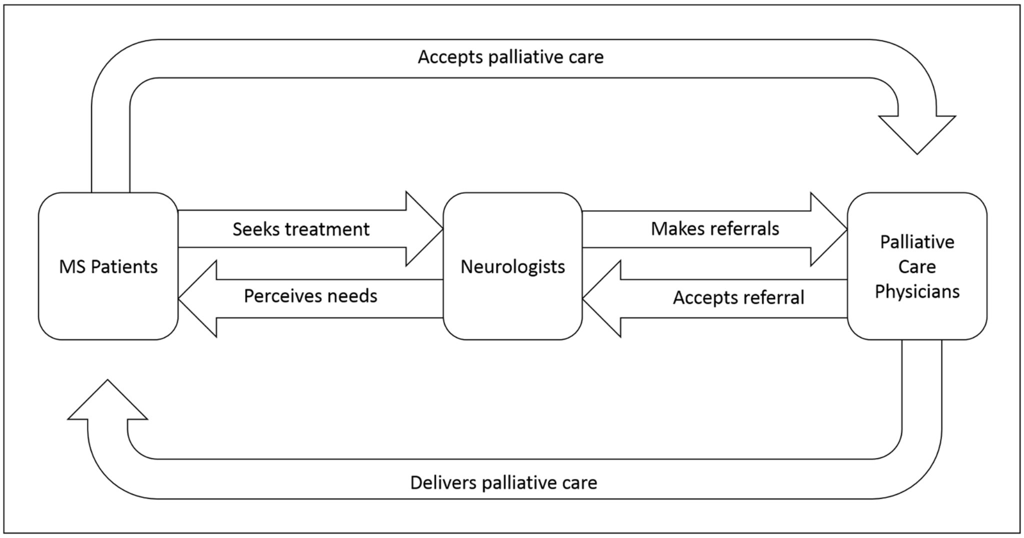


Fig. 1. Conceptual model of the referral and provision of palliative care to MS patients.

making at the end-of-life. The need for palliative care, they argued, was based on the individual's needs and not the diagnosis or stage of illness.

> It doesn't have to be a patient who is nearing the end of life… so as long as we identify that the patient is suffering, we are able to provide some form of palliation to comfort and relieve their suffering. (PCD04)

The patients and neurologists also struggled to identify any future health and palliative care needs that MS patients might have. Both groups spoke of rarely having discussions, if ever, on what the patients might face in the future and how to prepare for it. Both groups expressed a mutual feeling of discomfort and reluctance in having these discussions. For the patients, the reluctance was rooted in the fear of what an uncertain future might bring in terms of disability.

> I try not to think about it because if you think about it too much, this is where you start getting depressed. (PT01)

On the other hand, the neurologists were concerned with causing undue distress to the patients and their caregivers.

> We don't discuss with them too much because multiple sclerosis is an unpredictable disease… you don't want to be a messenger of doom yet. (NEU01)

MS patients who were severely disabled or bedbound were often unable to leave their homes for follow-up visits making it difficult for neurologists to identify their palliative care needs.

> I think most of the patients in this situation are either at home, unable to come to clinic or we presume lost to follow up, so in that case, I wouldn't know when they would need palliative care also. (NEU05)

3.5. *Theme: barriers to palliative care*

Several barriers to the provision of palliative care to MS patients were identified (see Fig. 2). One such barrier was the negative perception that patients and neurologists held towards palliative care that made it less likely for referrals to be made or accepted.

The differences in how patients, neurologists, and palliative care physicians understood the role of palliative care and the needs of MS patients also created barriers. Neurologists struggled with referring patients to palliative care as they did not have a clear understanding of when and how palliative care could help. Palliative care physicians, on the other hand, did not feel sufficiently familiar with MS to be able to advise the neurologists on this matter. As a result, referrals to palliative care would often be made at the end-of-life, if at all, or when the neurologists felt that they no longer had any role in the management of the patient.

The uncertainty among MS patients regarding the role of palliative care made it harder for them to accept palliative care. According to the palliative care physicians, an early introduction was important to help patients understand and accept palliative care. Despite that, none of the patients recall ever receiving such an introduction. The task of introducing palliative care often fell to the neurologists but this was hampered by the reluctance of the neurologists to do so due to the fear of causing undue distress. Consequently, the patients were left unsure of why and when they might require palliative care.

The lack of discussions between patients and the neurologists regarding the future needs of the patient and the inability of severely ill patients to continue following up with the neurologists also created barriers. As a result, patients eventually develop palliative care needs that go unidentified and untreated by palliative care.

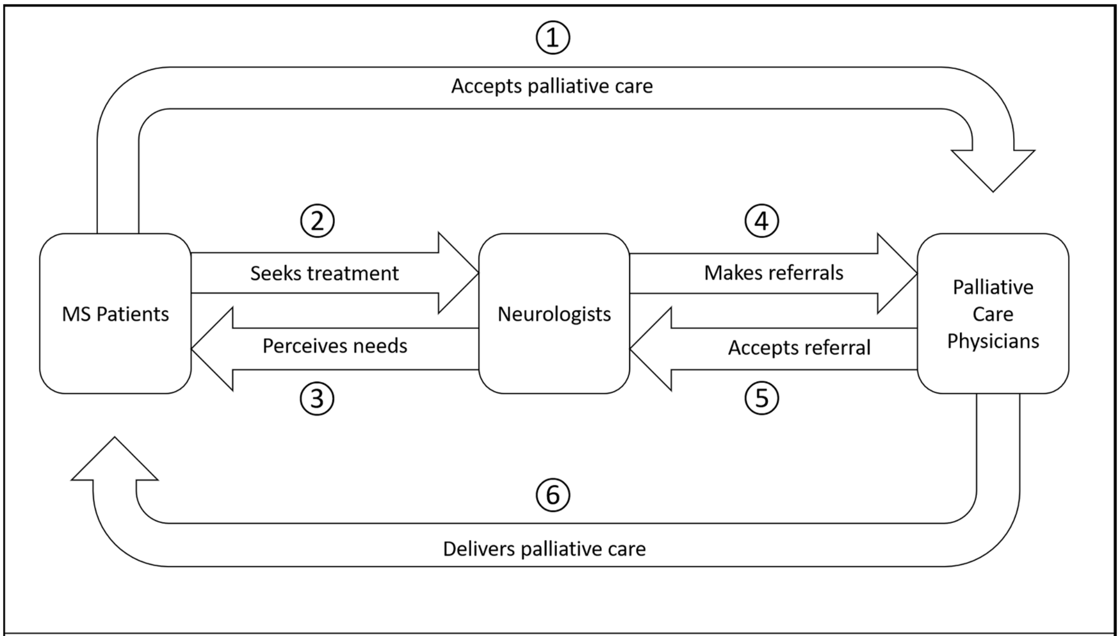
> Both sides are unsure. Doctors aren't sure when to refer. Patients don't know whether they are supposed to be seeking out palliative care, as well. (PCD01)

Palliative care physicians described how the scarcity of palliative care physicians and their lack of experience working with MS patients resulted in hesitation to take on MS patients. Consequently, some palliative care physicians would only take on MS patients that were clearly experiencing physical forms of suffering or were at the end-of-life. The lack of palliative care staff and resources also impaired their ability to deliver palliative care to MS patients.

> Without more manpower, our capacity to take on cases and patients is limited because we don't want to be in a situation where we are only giving touch and go services. So we constrain ourselves in order to provide the level of care that we think is right for the patients that we are able to take on. In the hospital as well, we do not have a dedicated ward of our own which makes it difficult for us to admit patients who need longer term palliative care. (PCD04)

3.6. *Theme: improving access*

The participants provided suggestions to improve the understanding of palliative care for MS among patients, neurologists, and palliative



Barriers	
① • Lack of awareness or uncertainty regarding role and function of palliative care • Negatively associated palliative care with end-of-life and dying • Unsure of how palliative care can help MS patients • Do not consider themselves as needing palliative care • Unsure when palliative care would be required	② • Reluctance to discuss future needs or end-of-life issues • Severely ill MS patients often do not return to the hospital for follow-up
③ • Uncertainty and variability in progression of MS • Reluctance to discuss future needs or end-of-life issues • Severely ill MS patients often do not return to the hospital for follow-up	④ • Palliative care perceived as only for patients at end-of-life • Referral to palliative care seen as abandoning patient • Do not have clear understanding of how palliative care can help MS patients • Uncertainty and variability in progression of MS
⑤ • Unfamiliar with the needs of MS patients • Some palliative care physicians only accept patients experiencing suffering or at end-of-life	⑥ • Insufficient resources to provide dedicated care to MS patients • Unfamiliar with the needs of MS patients • Lack of home care

Fig. 2. Barriers to the provision of palliative care to MS patients.

care physicians. Both patients and palliative care physicians suggested that an early introduction to palliative care would help patients understand the role of palliative care and how to access it, improving their acceptance. The patients also recommended more discussions between patients and neurologists to improve understanding of their future health and palliative care needs.

> Yes, I would love to have a doctor who would be, "Oh, okay. Talk to me about it." They don't do it here. Then based on what I tell him, if he tells me he thinks I need palliative care, and for what reasons, I think it would make more sense to me. (PT07)

Integrating palliative care physicians into the neurology team was also suggested as a way to improve the shared understanding between the two specialties. Knowledge on both palliative care and MS could be shared seamlessly and palliative care could be delivered to patients, without the need for referrals. Palliative care physicians would also be able to identify patients with palliative care needs earlier.

> I think it would also be good if we could then have them join in some of our grand rounds so that we can let them see the patients together during the rounds without us having to refer the patients to them. I think if we can avoid unnecessarily scaring the patients by telling them we are referring them to palliative care, it would be better. (NEU05)

The palliative care physicians and neurologists also agreed that more resources were needed for palliative care.

4. Discussion

This study reinforces the neglected status of MS patients in Malaysia who face barriers in accessing and receiving palliative care; even though MS has previously been identified as a key area for palliative care in Malaysia (Lim et al., 2010).

Our findings indicate that these barriers largely emerge from the perceptions held by patients and neurologists toward palliative care as well as the lack of a common understanding between MS patients, neurologists, and palliative care physicians about the role that palliative care can have in the management of MS and the palliative care needs of MS patients. These barriers are similar to those have been described in previous studies conducted in the UK, Germany, and Italy (Golla et al., 2012; Edmonds et al., 2010; Strupp et al., 2016; Higginson et al., 2009; Higginson et al., 2011; Golla et al., 2014; Knies et al., 2015; Borreani et al., 2014). This suggests that despite the wide differences in practice settings and MS prevalence, the interventions described in the literature to address these common barriers to palliative care in MS may be adapted and applied in Malaysia.

What is striking, however, is that these barriers to palliative care are actually reinforced by the current care pathway. The care pathway provides numerous opportunities for barriers to emerge, making it easier not to provide palliative care to MS patients than to provide it. A care pathway that involves multiple gatekeepers requires a system of communication in place that ensures shared understanding and continuity of care (Dudley et al., 2019; Furman et al., 2007; Lim, 2009; Gardiner et al., 2012). Our study suggests that there is no such system of communication in place.

The care pathway also casts palliative care as an end-stage destination to which patients who are no longer suited for treatment are moved. It is unsurprising, therefore, that many of the barriers to palliative care appear to arise from a struggle to delay "relegation" or to avoid being mistakenly "relegated" ahead of schedule. If, however, palliative care is accepted as an approach that is parallel or even indistinguishable from medical treatment, then it is clear that the current care pathway is not only irrational, it stands in the way of addressing many of the problems of misunderstanding which forms the core of many barriers towards palliative care. As such, a move away from the current referral-based care pathway to an integrated model of care is needed to improve access to palliative care for MS patients (Strupp et al., 2016; Gardiner et al., 2012).

It is also worth considering the regional factors that impede the access to palliative care services for MS patients. For one, there appears to be little interest in the development of palliative care services for MS patients despite the increasing prevalence of MS in the Asia Pacific region (Cheong et al., 2018a,b). This is further complicated by the scarcity of epidemiological data on MS required for the resourcing and development of healthcare services for this patient population (Cheong et al., 2018b). As such, palliative care services for MS patients may continue to be under-resourced and the palliative care needs of MS patients neglected.

5. Conclusion

Despite the global consensus on the need for palliative care in multiple sclerosis, patients with multiple sclerosis in Malaysia face several barriers in accessing palliative care. Overcoming these barriers will require a comprehensive effort towards improving the shared understanding of palliative care and its role in MS amongst healthcare professionals and MS patients. The existing care pathway also needs to be reformed to ensure that it improves access to palliative care for MS patients, rather than restricting it.

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Conflicts of interest

WLC, DM, NW, and DDR declare that they have no conflict of interest.

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