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Uncovering patterns of real-world psychological support seeking and the patient experience in multiple sclerosis

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ABSTRACT

Background: With the rate of psychological disorder being disproportionately high in people with Multiple Sclerosis (pwMS), it is important that they receive adequate psychological support. While there are informal and more formal sources of psychological support for pwMS available, there is a paucity of research in understanding the actual pattern of support that pwMS interact with in a real-world context. We aimed to understand this by examining the pattern of access across different sources of psychological support in the same large cohort of pwMS, and their experiences of support received. We also explore this in the context of different MS symptom profiles and demographics.

Method: In an online survey, we asked 565 pwMS to report on their actual pattern of usage and their experience of receiving psychological support from four key sources - friends/family/peers, MS organisations/charities, MS specialist nurses and mental health professionals. Demographic and clinical data was also gathered about their MS profile and symptoms.

Results: Friends/family/peers were rated as the most common, helpful and easy to access source of psychological support. However, most participants received psychological support from multiple sources, almost always in conjunction with support from friends/family/peers. Demographic and MS related factors predicted whether patients accessed each source or not. Younger pwMS and those more recently diagnosed were more likely to avail of support from friend/family/peers. The more patients were bothered by their symptoms the more likely they were to avail of psychological support from more sources. In particular, pwMS who are more bothered by fatigue and psychological symptoms were more likely to avail of support from mental health professionals. Overall, the helpfulness of support depended largely on how well the support provider knew the pwMS as a person and MS as a condition, as well as the level of emotional and practical skills support provided.

Conclusion: People with MS need to access multiple sources of support to meet the full spectrum of psychological needs as and when needed; friends/family/peers and mental health professionals for emotional support, and MS organisations/charities and specialist MS nurses for learning skills to manage their MS. This points towards the need to take a collaborative approach amongst the different sources of support to ensure all needs can be most effectively met.

1. Introduction

Due to the nature of Multiple Sclerosis (MS) being unpredictable and incurable, it is usual for people to go through psychological distress following diagnosis (Benito-Leon et al., 2003). This is commonly exhibited in the form of anxiety, depression, negative affect and sometimes with symptoms of trauma (Counsell et al., 2013). It is therefore important that people with MS receive the appropriate psychological support to deal with these psychological difficulties (Davis et al., 2021). Psychological support has been divided into different components: emotional support (such as comforting, listening and being available for them; Koopman et al., 2006), information provision (Topcu et al., 2020; While et al., 2009) and concrete support (making practical care arrangements; Harrison and Stuifbergen, 2002). With this in mind, it might be expected that different sources and types of support might be more or less appropriate for providing the different components of psychological support (Machin and Stevenson, 1997).

Friends and family have been identified as a means to maintain social

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identity (Barker et al., 2018), transitioning to life with MS whilst maintaining existing roles as much as possible (Tabuteau, Haslam and Mewse, 2016) promoting active, adaptive coping strategies (Rommer et al., 2017). It is not surprising therefore that they have also been identified as the most important providers of support by 89% of respondents in a study comparing different sources of support to pwMS (While et al., 2009). Additionally, MS peers have been identified as most important in providing information by 68% of respondents and providing emotional support by 45% (While et al., 2009). Active engagement in peer support groups has been linked to positive mental health outcomes (Wakefield et al., 2013) perhaps due to the process of 'normalising' MS and its associated symptoms through contact with others in a similar situation (Ytterberg et al., 2008).

Overall, people with MS report that they are self-managing well with support from significant others, or that antidepressant medication keeps more severe mental health problems under control (Methley et al., 2017). Additionally, the feelings that come with a diagnosis of MS are often expected as a natural consequence of the diagnosis. Therefore, help seeking beyond what is immediately available from significant others may not occur (Alderson et al., 2014). It is only then, when the demands of daily life become too much, that help seeking behaviour occurs (Maxwell (2005). The present study aims to expand on this further by exploring patterns of access to psychological support.

There is little literature available about psychological support provided by MS organisations and charities. However, in a study that does address this source of support, 19% of pwMS identified MS charities as important in providing support (While et al., 2009).

The role of the MS specialist nurse is important for pwMS (Johnson (2003) and has been linked to improved health related quality of life (Heiskanen and Pietila, 2009). However, with the multifaceted role of the MS nurse it can become difficult to meet all their needs (Meehan and Doody, 2020) due to limited time and lack of skills to address psychological concerns (Methley et al., 2017). The patient perspective matches this to some degree in that patients often chose not to mention psychological difficulties due to these same barriers (Cowan et al., 2020), as well as the overreliance on drug treatment (Senders et al., 2016). Despite this, a survey addressing care needs in people with MS found that 28% of pwMS identified the MS nurse specialist as important in providing support with 89% identifying them as most appropriate for providing information and 60% for emotional support (While et al., 2009) with the expectation that there should be the opportunity to discuss and have concerns listened to (Heiskanen and Pietila, 2009).

Although psychological interventions for pwMS are usually delivered by mental health professionals, there are inconsistencies between the patient and health care providers in understanding who should be the one to provide or refer for additional mental health care creating a barrier to accessing crucial services in pwMS (While et al., 2009; Methley et al., 2017). This has frequently been cited as a problem, particularly in the earlier stages of the MS diagnosis when such services are reportedly more in demand (Topcu et al., 2020). However, when accessed, services have provided some success, but with the heterogeneity between intervention design and participant characteristics, results remain somewhat inconclusive (Thomas et al., 2006).

Overall, regardless of the source of psychological support, several factors have been identified as necessary for successful support, such as knowing the individual (Fairhurst and May 2001), knowledge of MS (Forbes et al., 2007; Chiu et al., 2020), awareness of what's available (Edmonds et al., 2007), positive past experiences with the source, that it is offered without request (Methley et al., 2017) accessibility and having a sympathetic and kind approach (Ytterberg et al., 2008). Additionally, other demographic and disease related factors may determine whether people feel the need to seek psychological support or not. For example, whether they are working or not, or their ability to work is impacted (Bass et al., 2020), age (Kraft et al., 1986), gender (Heiskanan and Pietila, 2009) time since diagnosis (Heiskanan and Pietila, 2009; Ytterberg et al., 2008), and impact of certain symptoms (Chwastiak et al., 2005; Johansson et al., 2009).

Psychological support has consistently been identified as the greatest unmet need for people with MS (Ponzio et al., 2015). Research to date has allowed for some level of exploration of the experience of support from different sources, however, this is often explored in the context of opinions on what should be available rather than the actual lived experience of accessing different sources of psychological support. Additionally, when the lived experienced have been explored, these have generally been evaluated independently within different cohorts in separate studies. This therefore does not allow for a comparison of the different sources of support from the patient perspective. The current research explores different types of support simultaneously within the same cohort allowing for comparisons and patterns to been explored further. This, in conjunction with other clinically relevant data available from the same survey, such as demographic and illness related variables, allows for a deeper exploration of other factors important in understanding patterns of psychological support for pwMS in terms of who is availing of what and why, as well as what is working and not from the patient perspective.

2. Materials and methods

An online survey was conducted that asked questions relating to psychological support received from 4 sources: friends/family/peers, MS organisations/charities, MS specialist nurses and mental health professionals. Participants were recruited via MS organization's newsletters and online support groups on social media.

Participants were asked questions regarding how helpful they found each source, how easy they were to access, how frequently they accessed each source and what type of psychological support they received from each source.

Participants were also asked open text questions to provide further insight into why they did or not choose to access each source of support and if they did access it, what was helpful and not. This information was used alongside the quantitative data to provide a more in depth understanding of the lived experienced of psychological support from different sources from the patient perspective.

As part of the full survey, participants were also asked to rate how bothersome broad clusters of common MS symptoms were (fatigue, psychological, motor, sensory, cognitive).

2.1. Participants

The sample consisted of 565 people with MS; 492 females (87%) and 73 males (13%) aged between 20 and 75 ($M = 47.2$, $SD = 12.1$) diagnosed for between <1 year and 44 years ($M = 10.2$, $SD = 9.1$). The majority of the sample had relapse remitting MS ($n = 400$, 71%), with 50 primary progressive patients (9%), 84 secondary progressive patients (15%), 9 with clinically isolated syndrome (1%), and 22 unsure (4%).

2.2. Ethical considerations

Ethical approval was obtained from the University of Reading Ethics Committee. This study was performed in accordance with the Helsinki Declaration of 1964 and its later amendments. Participants provided written informed consent digitally before completing the survey.

3. Results

The most frequently accessed source of psychological support was from friends/family/peers, accessed by 482 people (85%). Approximately half of the sample accessed MS organisations/charities (56%), MS specialist nurses (52%) and mental health professionals (53%). Table 1 also provides a comparison of when, why and ease of access of these different sources of support, which will be reported further below.

To provide further insight on psychological support engaged with,

Table 1
Summary of support source characteristics.

	Friends/ family/ peers	MS organisations/ charities	MS specialist nurses	Mental health professionals
Number availed (% out of 565)	85% ($n = 482$)	56% ($n = 318$)	52% ($n = 291$)	53% ($n = 302$)
Accessed for an MS specific psychological issue	40% ($n = 194$)	43% ($n = 138$)	48% ($n = 141$)	47% ($n = 141$)
*Accessed for emotional support**	83% ($n = 399$)	44% ($n = 141$)	44% ($n = 127$)	62% ($n = 186$)
*Accessed to explore new ways to manage MS**	24% ($n = 118$)	62% ($n = 196$)	68% ($n = 197$)	35% ($n = 105$)
Ease of access (1 = very easy, 5 = very difficult)	$M = 2.2$ ($SD = 1.3$)	$M = 2.3$ ($SD = 1.3$)	$M = 2.5$ ($SD = 1.4$)	$M = 2.7$ ($SD = 1.5$)
Helpfulness (1 = not at all helpful, 10 = very helpful)	$M = 7.5$ ($SD = 2.3$)	$M = 6.4$ ($SD = 2.8$)	$M = 6.2$ ($SD = 3.0$)	$M = 6.7$ ($SD = 3.1$)

* participants could select multiple reasons for choosing to access each source.

we report on common responses (including frequency of occurrence) from participants' written explanations, highlighting the lived experience of pwMS using their own words (in quotation marks) below.

3.1. Friends/family/peers

The most common reason for not seeking support from friends/family/peers was not wanting to be a *'burden'* on them, usually because they have their own *'issues'* to deal with (23%).

This source of support was rated as the easiest to access of all the sources explored ($M = 2.2$, $SD = 1.3$). The majority of people who accessed this source of support reported that the main thing that was gained from this source was the emotional support in having someone to talk to about their MS (83%). This pattern was reflected in participants' open text responses where the most common reasons stated for seeking support from friends/family/peers was accessibility and responsiveness (29%) and familiarity and knowing the individual with MS (15%). Given this proximity and type of existing relationship, participants often reported it was the *'logical option'* to receive *'first line support'* from this source.

Other responses focused on being able to talk to someone trusted who would be non-judgemental and compassionate, educating them about MS and the *'new "me"'*, getting instrumental support and because they did not want to go through it alone. 44 people (10%) specifically spoke of seeking support from MS peers for validation, so as to not feel *'alone in my disease'* helping to *'reduce some of the unknowns'*.

Family/friends/peer support was rated as the most helpful source of psychological support compared to the other sources explored ($M = 7.5$, $SD = 2.3$). Especially valued was the emotional support provided to give reassurance and comfort in *'knowing people care'*, *'love me'* and *'are having my back'*, providing an opportunity to talk or *'just vent'* and to *'encourage me to contact more specialist services'* (29%). Other responses focused on factors such as the fact that they knew each other well and can *'navigate'* through difficulties together in order to *'flow'* with it, with the *'knowledge I wasn't alone'*.

The least helpful thing noted about support from family/friends/peers was the lack of knowledge of MS, or even not acknowledging it all because *'unless you've had MS or mental health training, you really can't understand someone with MS'* (23%). Other unhelpful aspects usually focused on providing *'unsolicited advice'*, *'unrealistic suggestions'* or non-scientific solutions to cure MS, such as *'the group of people who would send me emails with the "diets that healed their MS", "go get stung by bees", "diet soda causes MS", the list of crazy cures is endless'* and *'too many times they tried to do more than listen and told me what I "should" do which made me angry'* or by trivialising the illness with comments such as *'you don't look disabled'* and *'then there's those who take the news and make a positive spin on it.. you'll be grand, you wait and see, the treatments these days are incredible. Or I know a girl who was diagnosed and she continues to work and lead a very normal life....'*.

3.2. MS organisations/charities

The main reason for not seeking psychological support from this source was not being aware that such options are available (28%), often because people *'didn't think of MS organisations as a source for psychological support'* or *'nothing was offered'*. Others reported that they don't need it (26%) usually because they are satisfied and *'felt very supported psychologically by family and friends and did not feel the need to access further support'*, *'dealt with it in my own way'* or did *'not feel these organisations would offer support at my preferred level of clinical detail'*.

Of those who accessed this type of support, more people got support in exploring new skills to manage their MS (62%) than for emotional support (44%). Open text responses supported this with the most common reason for seeking psychological support from MS organisations/charities was to get *'informed'*, *'accurate'*, *'specialised'* and *'trustworthy'* information about MS (28%), usually as a means to increase understanding of the condition and *'understand better what I was feeling'* and *'to understand how I could deal with my MS'* often by getting *'answers from people who knew "exactly" what I was going through'* because *'maybe they were better at understanding the psychological impact of MS'* ultimately leading to feelings of *'validation'*. Another top reason for seeking this source of support was that the source is perceived to be impartial, and the people are unknown to the individual (11%) and its availability at *'the click of a button'*. Otherwise, reasons include using this source as a means to educate loved ones and that the level of support was the *'right level for the need'* due to being *'not too clinical'*.

The most helpful thing about this support was reported as being able to gain a sense of not being alone either through gaining an understanding of what MS is through the *'wealth of'* resources and materials provided where *'information was clear and directed, and gave practical next steps'* that was *'factual and simple to understand'* (29%) or through talking to *'others like me'* with MS who are *'going through the same thing'* provides *'comfort of knowing you're not the only one going through the myriad of odd and difficult to explain symptoms'* which *'made me more knowledgeable of MS'* (20%).

The least helpful thing about this type of support was that information provided is *'generic'*, *'too general'* and not personalised enough to meet *'specific needs'*. It was *'just written information'*, not delivered face to face and therefore *'not the same as a conversation'* (13%). Other comments about what was not helpful about this type of support featured *'having to sort through organizations to ferret out ones that were helpful for everyone versus those that were out to promote or exploit products and people'* as well as the lack of trust for organisations that are viewed as being *'driven by the pharmaceutical companies'*.

3.3. Specialist MS nurses

Most people who did not avail of support from this source did not do so because it was not offered or available to them (37%) or that they did not feel like they needed it as they got support elsewhere, such as *'family and friends and didn't feel I had to go outside the group'* (15%). Otherwise, people felt it was not appropriate as they felt their role was *'geared towards medical problems'* and for *'treatment queries'*, or that they were not responsive, either *'too busy to care'* or *'if you find the number there's rarely anyone to answer it'*.

As with MS organisations/charities, specialist MS nurses were also accessed more for learning new skills to manage MS (68%) than emotional support (44%). The reasons for this were reflected in open text responses. This source of psychological support was most commonly accessed because it was just provided or offered as part of treatment and they were therefore often the *'main contact point for all MS related things'* and the *'point of reference for arranging blood tests, collecting medication etc., so I had to interact with her'* or *'because they are experts and if can't help, as an expert, they can signpost appropriately'*, its *'part of the job'* (33%). Otherwise, the next most common reason was because they felt they needed advice and information with regards to an MS related issue such as a relapse or medication (16%). Other responses focused on feeling they were most appropriate due to their knowledge of MS and their access to individual medical notes and therefore *'have been with me through the whole journey so they know my ms just as well as I do'*, providing *'reassurance'* and *'support no matter how big or small'*.

The most helpful thing about this type of support was reported as the *'practical advice'* and *'specific examples and solutions'* from someone with *'professional expertise'*, *'knowledge'* and a *'good understanding about me and my health'* or otherwise referring where necessary such as providing *'proactive support in getting more help e.g. with physiotherapy, urinary issues'* (27%) and that support was personalised, *'focused on me'* and face to face with someone who is *'compassionate and kind, reassuring and helpful'*, *'supportive'* and *'spent time listening to my concerns'* whilst *'delivered on my "level"'* (25%).

The least helpful thing was the difficulty in accessing the MS nurse, either due to *'lengthy wait for appointment'*, *'difficult to find phone number'* and *'when you do find the number there's rarely anyone there'* usually because *'they're very busy'* (18%) and the focus on *'drug protocol'* and being *'mostly concerned if I was taking the drug'* or *'only wanted to discuss increasing my medication'* rather than psychological support (9%). A couple of participants specifically mentioned that when psychological support was requested, MS nurses reportedly *'made clear that psychological support was not on offer as part of what the MS team did'* and they were unable to suggest *'ways to deal with the psychological impact of this [pain], despite me requesting this kind of support directly'*. This may be as the feeling was that they are *'not trained in counselling'* or providing psychological support and the *'very limited resources'* available to them so *'there is only so much they can do'* due to the *'many constraints on their time'*.

3.4. Mental health professionals

The main reason for not seeking support from mental health professionals was that pwMS were happy with support they received elsewhere (54%). The next most common response was not knowing what's available (35%).

As with accessing friend/family/peers, people most commonly received emotional support from this source (62%), rather than exploring ways to manage MS (35%).

The most helpful thing about this source of support was learning skills to manage emotions, learning *'coping mechanisms'* and gaining *'emotional control'* and *'insight'* through exploring *'different perspectives'* or *'another way of looking at a problem'*, addressing *'reasons and opportunities for making changes to improve my mental health'* enabling the ability to *'figure many things out for myself'* (28%). Otherwise, the opportunity to *'get things off my chest'*, *'talk through things'* and *'work through feelings and emotions'* in a safe space *'freely without worrying about the topics' 'without judgement'* (13%) and getting support from someone who is *'understanding'*, *'validating'*, and *'compassionate'* who is easy to talk to (13%) featured most frequently amongst those who had availed of this source of support.

On the other hand, the *'lack of understanding'*, *'lack of MS knowledge'*, *'acknowledgment'*, or not being *'tailored to MS or even to disability general [ly]'* were noted as unhelpful factors from this source of support (14%). Poor relations with the therapist due to *'not connecting'* or it being a *'little tricky finding a psychologist who ''clicked' with me and MS'* were also reported as a the most common unhelpful aspects of this source of support (14%). Otherwise, factors such as the treatment not being long enough – *'finished before I was ready'*, or with no follow-up or *'review'*, were noted as unhelpful. Theory dependant assumptions incompatible with beliefs that may have been held about the type of psychological support engaged in were also reported, such as the suggestion that *'my MS was because I was unable to express my inner psychological state'*, laying *'responsibility for how one is feeling with the individual'* or discarding the impact of physiological changes and *'ignores any impact from lesions'* and that it was not provided one to one were also reported as unhelpful.

3.5. Pattern of psychological support across multiple sources

To examine the overall pattern of support utilised by MS participants, Table 2 shows a breakdown of the different combinations of support accessed. The most common support pattern found in 40% of participants was accessing support from all sources i.e. family/friends/peers, MS organisations/charities and/or MS specialist nurse and a mental health professional. On the other hand, 7% did not access support from any of these sources at all. 6% of participants reported receiving support only from 1 source - either MS organisations/charities/MS specialist nurses or mental health professionals. Otherwise, support from these sources were accessed alongside support from other sources, particularly friends/family/peers, who were accessed in combination with at least one other type of support by 74% of the sample.

3.6. Psychological support access according to symptom profile

Table 3 presents a breakdown of the frequency of psychological support sources accessed according to level of bother from MS symptom clusters.

Aside from support from friends/family/peers that was accessed equally regardless of the level of bother experienced as a result of all different symptom clusters (> 79%), support from other sources was availed of progressively more by those who were more bothered by each different symptom cluster. Additionally, even though increase in access is observed according to level of bother for all symptoms, there is little difference between the sources of support at each level of bother, usually with <10% difference between each source for each symptom and level of bother. For example, with sensory symptoms, around 40% of people with little/no bother accessed support from either of the sources, between 50 and 58% for those with somewhat bothersome symptoms, and between 55 and 58% for very bothersome symptoms. However, a deviation from this pattern lies in relation to fatigue and psychological symptoms where a dramatic rise in access to mental health professionals is observed as the level of bother increases.

3.7. Psychological support access according to demographic and MS related factors

Demographic and MS related variables and level of bother from

Table 2
Combinations of psychological support accessed.

Friend/ family/ peers	MS organisations/charities and/or MS specialist nurse*	Mental health professional	Frequency (%)
x	x	x	38 (7%)
√	x	x	64 (11%)
x	√	x	15 (3%)
x	x	√	14 (3%)
√	√	x	146 (26%)
√	x	√	46 (8%)
x	√	√	16 (3%)
√	√	√	226 (40%)

[*] figures for MS organisations/charities and MS specialist nurses are combined due to similar access figures for both sources.

Table 3
Frequency of psychological support access according to level of bother from symptom clusters.

		Friends/family/peers (n = 482)	MS organisations/charities (n = 318)	MS specialist nurses (n = 291)	Mental health professionals (n = 302)
Symptom cluster	**Level of symptom bother**				
Fatigue	*Little/no (n = 65)*	85%	39%	40%	28%
	Somewhat (n = 156)	85%	55%	47%	47%
	Very (n = 344)	86%	61%	56%	61%
Psychological	*Little/no (n = 116)*	80%	40%	44%	28%
	Somewhat (n = 183)	91%	60%	54%	51%
	Very (n = 266)	84%	61%	53%	66%
Cognitive	*Little/no (n = 125)*	82%	44%	41%	42%
	Somewhat (n = 219)	90%	62%	53%	52%
	Very (n = 221)	82%	58%	56%	62%
Sensory	*Little/no (n = 57)*	79%	44%	40%	40%
	Somewhat (n = 218)	86%	58%	50%	51%
	Very (n = 290)	86%	58%	55%	58%
Motor	*Little/no (n = 132)*	85%	53%	52%	44%
	Somewhat (n = 210)	87%	55%	51%	55%
	Very (n = 223)	85%	60%	52%	58%

symptoms were entered into a binomial regression to determine who accesses each source of support. These variables significantly predicted whether participants accessed support from friends/family/peers ($\chi^2(13) = 41.90, p < .001$), MS organisations/charities ($\chi^2(13) = 37.56, p < .001$), MS nurses ($\chi^2(13) = 25.95, p < .05$). and mental health professionals ($\chi^2(13) = 71.66, p < .001$) predicting between 7 and 16% of variance in whether someone accessed the source or not. In particular, younger people, those living with others, those diagnosed for less time and those with a progressive diagnosis were more likely to avail of support from friends/family/peers and those with higher levels of bother from fatigue and psychological were more likely to access support from mental health professionals.

4. Discussion

The aim of this study was to uncover real-world patterns of psychological support in pwMS, and to understand their experiences of seeking and receiving this support.

Friends/family/peers were the most accessed source of support accessed by the majority of the sample with MS organisations/charities, MS specialist nurses and mental health professionals each accessed by around half the sample. The most common support pattern was to access all types of support, with very few accessing only one source. Friends/family/peers and mental health professionals were most commonly accessed for emotional support, whilst MS organisations/charities and MS specialist nurses were most commonly accessed to learn new skills to manage MS. PwMS reported that availability and expectations were factors that determined what people desire and find helpful from each source of support. Findings indicate that the utility of support was increased (or decreased) according to how well the support provider knows the individual and MS as a condition.

Overall, demographic and illness related factors significantly predicted whether participants accessed different sources of support. In particular, demographic factors were the strongest predictors of who accessed support from friends/family/peers and symptom bother (from fatigue and psychological symptoms) was the strongest predictor of who accessed support from mental health professionals.

4.1. *What is helpful about different sources of support?*

Findings from the current study are largely consistent with existing research in the area whilst providing additional depth and explanation to such findings. For example, in line with what participants identified as most helpful about each source of support, consistent with previous findings, peer support presents the opportunity to feel ‘normal’ through interaction with others in the same situation (Forman and Lincoln, 2010). Likewise, this feeling of ‘normality’ can be established through interactions with people (professionals, or otherwise) that know the patient well and have been able to develop a trusting relationship with (Joseph-Williams et al., 2014). This explains why knowing the pwMS well accounted for helpful psychological support from all sources in the present study. However, at the same time, restricted resources can prevent such interactions from occurring in the professional context (Grose, Freeman and Skirton, 2012). This is particularly the case in the nursing setting where consultations, in an already stretched service (Chiu et al., 2019), are limited to a short amount of time where the first priority lies on physical assessment despite realising the pressing need of dealing with mental health problems (Methley et al., 2017). This also leads patients to avoid talking about psychological problems due to not wanting to ‘bother’ them (Soundy et al., 2016) as well as the focus of such consultations on drug treatment (Senders et al., 2016). Although the latter finding related to nurses in general, this present study provides evidence to suggest that same findings apply to care provided by MS specialist nurses also

As well as the importance of knowing the individual, knowledge about MS was also highlighted as a factor that influenced the experience of different sources of support in this study. This finding is consistent with other studies that have also concluded this as an important component of support in this population from the patient perspective (Ytterberg et al., 2008). In the context of support provided by MS organisations/charities, this focus on knowledge of MS seemed to be the factor that yielded positive views of this source of support in this study satisfying a need that has been identified as lacking (Kinyanjui et al., 2018). Despite the fact that MS organisations/charities can provide needed information, in some cases people simply weren't aware of what's available which influenced level of access to this source, or that such services were not available locally to them (McCabe et al., 2015). This experience was notably the same with regards to accessing support from mental health professionals (Edmonds et al., 2007).

4.2. Why access multiple sources of support?

Previous studies have questioned why, despite the high prevalence of mental health problems, so few people actually access professional mental health support (Minden et al., 2013; Forbes et al., 2007). The present study supported previous conclusions that psychological support needs are being sufficiently managed through support from friends/family/peers or antidepressant medication (Methley et al., 2017) and the need to seek support from mental health professionals arises only when impairments lead to psychological distress above and beyond what the layperson can manage (McCabe et al., 2015). This was confirmed in the present study in several ways. Firstly, through directly saying that they chose not to access support from mental health professionals because they were happy with support from other sources and mood medication. Secondly, this pattern is reflected in the finding that support from friends/family/peers are utilised by more people, and that the more bothered participants were by fatigue and psychological symptoms, the more likely they were to access support from mental health professionals. This additionally supports the conclusion that those with the most severe emotional problems are those who access professional psychological support (Forbes et al., 2007) and that fatigue and psychological symptoms are those that are more intrusive and impactful on daily life (Cowan et al., 2020) requiring additional professional support.

The present study identified that each source of psychological support satisfies different components of psychological support. Friends/family/peers and mental health professionals were availed of more frequently for emotional support and MS organisations/charities and MS specialist nurses for learning skills to manage MS usually through receiving information. This could provide another explanation as to why the majority of people access support from more than one source as it enables the patient to have the full spectrum of psychological support needs met.

Additionally, consistent with former findings (Ytterberg et al., 2008), needs change frequently for people with MS due to changing symptoms and impacts. This was directly found in the present study too and helps to explain the pattern of accessing multiple sources. That is, different needs come and go, and different sources fulfil these needs at different times. Therefore, different sources become more or less suitable at different times depending on the pressing need at the time.

4.3. Psychological support access according to demographic and MS related factors

Although it is important to understand psychological processes that may influence perceptions and access to care as a result (Fisher et al., 2020), the present study highlights the importance of not losing sight of the influence of demographic and illness related factors in understanding access to psychological support that are also noted to be of importance in previous research (Minden et al., 2007; McCabe et al., 2015).

Of particular relevance to the present study, it was found that those who were newly diagnosed were more likely to access support from friends/family/peers, indicating that they are first line of support upon first diagnosis and therefore a high level of importance is placed upon this source throughout the illness trajectory (Koopman et al., 2006; McCabe et al., 2015). This provides evidence to support the conclusion that support from this source provides a means to maintain existing identity in the transition to life with MS (Tabuteau, Haslam and Mewse., 2016).

A unique strength of the present study is that it allowed for exploration of different sources of support within the same cohort. This aided the identification of real-world patterns of support access and exploration of any underlying explanations for such patterns, why people chose to access each source, for what, and what was helpful and not helpful. Further research could investigate these patterns in closer detail, exploring specific types of psychological support and impact on wellbeing.

5. Conclusions

Friends/family/peers provide expected and ongoing emotional support for pwMS especially in the early stages following diagnosis. Support extends to other sources, as and when needed as other more pressing needs arise. Often this is as a result of the development of a new symptom that perhaps require a different type or level of support that would be better provided by another source more equipped with a better understanding of MS. This is particularly the case with fatigue and psychological symptoms that require a more professional level of mental health support due to their wider and harder hitting impact on daily life with MS.

People with MS need to access multiple sources of support to meet the full spectrum of psychological needs as and when needed; friends/family/peers and mental health professionals for emotional support, and MS organisations/charities and specialist MS nurses for learning skills to manage their MS.

Based on the findings of this study, it is suggested that close collaborations between the different sources of psychological support may provide a solution to overcoming some barriers present. For example, given the accessibility and importance of support from friends/family/peers, a collaboration with MS organisations to provide information about MS could help to overcome the current barrier of lack of knowledge of MS. This could be done with the support of mental health professionals in helping to teach skills to provide more effective emotional support. This may help to ease the burden that is experienced by the MS nurse in providing many different services to the MS patient if other stakeholders in MS care could also be involved in the task of providing psychological support to people with MS.

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Conflict of Interest

None.

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