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Psychotherapy and professional psychological support in multiple sclerosis: Uncovering patients' patterns of access and preferences

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ABSTRACT

Background: Whilst there is research on psychotherapy and professional psychological support (PPS) in people with Multiple Sclerosis (pwMS) in discrete randomised controlled trials, little is known about the different types of PPS pwMS access throughout the trajectory of their illness and their perceived helpfulness. Additionally, research on what pwMS's preferences are with regard to PPS is lacking.

Method: In an online cross-sectional survey study with 565 pwMS, we asked about the types of PPS pwMS had accessed and their preferences.

Results: Although 88% of the sample wanted PPS, only 53% of the sample had managed to access PPS. 40% of the entire sample currently wanted PPS but did not access it previously. The most common reason for this was because they were happy with the support they received from other sources (51%) and/or they were unaware of what was available to them (33%). 59% of those who had accessed PPS had accessed more than one type. The perceived level of helpfulness from PPS was rated as higher amongst those who had accessed more types of PPS. The most common combination of PPS accessed was a mixture of counselling with either cognitive behavioural therapy and/or mindfulness-based therapies. Counselling was the single-most accessed type of PPS. Most pwMS wanted PPS as a proactive means to either preserve and boost psychological well-being (37%) or learn skills to manage future difficulties as and when they arise (23%), rather than as a reaction to immediate pressing concerns (18%). The majority of pwMS showed a broad range of preferences regarding PPS and selected more than 5 types, with high interest in programmes with a self-management component, counselling and mindfulness-based interventions in particular.

Conclusions: Patient preferences for PPS highlight the need to take a proactive and preventative approach to preserve psychological wellbeing rather than only being provided in response to mental health crises. Psychological support should be made more readily available early on to fulfil this presently unmet need.

1. Introduction

There is a high prevalence of mental health problems in people with Multiple Sclerosis (pwMS; Boeschoten et al., 2017). Psychotherapy and professional support (PPS) has been consistently identified as one of the top unmet needs for pwMS. In a large sample of over 3000 pwMS, it was found that 60% had self-reported mental health problems. Less than half of this subgroup of the sample received the needed mental health treatment (Minden et al., 2013). In another large sample of over 1000 pwMS, PPS was reported as the top unmet need by nearly three quarters of the sample (Ponzio et al., 2015). Similarly, in a review of 50 studies that address healthcare and rehabilitation needs, it was found that psychological support needs were amongst the top 3 needs addressed in

the papers reviewed (Kinyanjui et al., 2018). This need was reportedly higher at the point of diagnosis, diminishing with time (Lorefice et al., 2013). However, these studies looked at if the need was met or not, rather than observing the specific type of PPS they accessed. Likewise, further exploration should be made into how pwMS would like to have the gap filled with which specific type of PPS.

As a result of the need for PPS in pwMS, various types of PPS have been examined in pwMS to alleviate mental health difficulties and improve quality of life. Whilst PPS is available through public and private healthcare services, specific statistics on the uptake according to medical conditions are not available. Randomised Controlled Trials (RCTs) have therefore received the majority of attention in studies exploring PPS in pwMS. On the most part, such studies compare

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different psychological approaches to a waitlist or treatment as usual comparator. Very few head-to-head studies comparing different types of PPS for pwMS have been conducted. Of the handful that do, Cognitive Behavioural Therapy (CBT) has been found to be effective in reducing distress and measures of depression compared to supportive listening (Moss-Morris et al., 2013), supportive expressive group (Mohr et al., 2001), or supportive psychotherapy comparators (Foley et al., 1987). A meta-analysis also revealed some support for CBT over mindfulness-based therapies when compared to treatment as usual or waitlist control groups with small to moderate effect sizes (Ghielen et al., 2019). However, it has also been suggested that second wave approaches like CBT that challenge beliefs may not always be helpful treatment for psychopathology (Hayes et al., 2006), particularly in chronic illness such as MS where common beliefs are often in fact true, such as the fact that MS is currently incurable. As a result, pwMS have reported CBT to be 'demanding', 'laborious' and 'somewhat stressful' (Gottberg et al., 2016). It has therefore been concluded that therapeutic approaches that promote acceptance (Han, 2021) and mindfulness (Simpson et al., 2014) may be more appropriate for a chronic and progressive conditions such as MS. Indeed, Mindfulness Based Stress Reduction (MBSR) and Acceptance and Commitment Therapy (ACT) interventions have yielded equally significant improvements in symptoms and emotional competencies in comparison to each other against a wait list control group comparator reporting medium to large effect sizes (Sadeghi-Bahmani et al., 2022). However, despite some evidence for the utility of PPS in pwMS, it does not seem to be widely available as a routine part of treatment outside of RCT studies.

Many RCTs have been conducted examining the impact of different types of PPS in pwMS, however little is understood about patient preferences for types of PPS. Healthcare and rehabilitation in this population tends to focus primarily on the physiological component of MS (Kinyanjui et al., 2018; Methley et al., 2017). Aside from a study that found patient-reported needs for information, regular assessment and a preference for psychotherapy over drug treatment (Hunter et al., 2021), studies that do address psychological support needs have not specifically addressed what type of PPS pwMS would like. Therefore, whilst there is research exploring different types of PPS in pwMS, very few studies have directly compared different types of PPS to one another in MS. Additionally, there is lack of research regarding access to PPS within the context of clinical care and little is known about what therapy approaches are deemed most suitable according to pwMS.

To address these research gaps, this study takes a novel approach where we ask the same cohort of pwMS to report on the different types of PPS they have accessed throughout their MS journey, and to reflect on their experience in order to provide information on their preferences. This allows for exploration of actual PPS accessed in everyday life in conjunction with patient preferences in order to better understand and inform PPS in MS.

2. Materials/methods

An online survey was conducted that asked about participants previous experiences of PPS, in terms of what types they had accessed. To clarify with participants who may be unsure of the different types of PPS, a brief description was provided within the survey. Participants were also asked their preferences and opinions with regards to type and format of PPS of delivery. As a novel study, no surveys were available that addressed the topics being investigated. As a result, the researchers developed a survey to address the constructs being explored and piloted it with three participants before launching the survey to ensure clarity and usability. Participants were presented with multiple options to select from as well as being provided with the opportunity to provide other open text responses if desired. Multiple responses were permitted where appropriate. Participants were recruited via MS societies and organisations globally as well as via social media platforms. All participants were patients with a self-reported diagnosis of MS received from a

medical professional. Data was collected between April 2020 and May 2021 and securely stored on the University of Reading's drive accessible only by the researchers involved in this study to ensure confidentiality. Quantitative data were analysed using IBM Statistical Package for the Social Sciences (SPSS) software version 25.0. Frequencies, percentages were used to determine the level of access and desired access to PPS. One-way ANOVAs were performed on the data to better understand further patterns of access including the relationship between how helpful PPS was rated and the amount of PPS accessed, and multiple regressions were performed on the data to explore the types of symptoms that predict access to PPS.

2.1. Participants

Table 1 shows the sample characteristics according to demographic and MS related factors.

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

3.1. PPS types: Accessed vs wanted

Out of the whole sample ($n = 565$), 302 pwMS successfully accessed PPS (53%), and 263 people (47%) did not. Previous research by Morris-Bankole and Ho (2022) showed that the top reasons pwMS did not access PPS is due to being happy with the support they receive elsewhere (54%), and they do not know what is available (35%). Further exploration of this dataset indicated that other reasons for not accessing PPS included not knowing how to find it ($n = 59$, 22%) and mental health professionals lack of knowledge ($n = 45$, 17%), understanding ($n = 41$, 16%) and experience ($n = 51$, 19%) in providing suitable psychological support to pwMS.

Of those who had not previously accessed PPS ($n = 263$), the vast majority ($n = 228$, 87%) currently want PPS. Of this subgroup of pwMS who did not access PPS previously ($n = 228$), but want it now, the top reasons for not accessing PPS before were also being happy with receiving support elsewhere such as from friends and family or MS organisations (51%) and not knowing what is available ($n = 75$, 33%). Only 35 pwMS (13%) do not currently want it because they are happy with the psychological support they receive from other sources. In terms of looking at the sample as a whole, the unmet need for access to PPS was

Table 1
Sample characteristics.

Gender (n,%)	Male	73 (13%)
	Female	492 (87%)
Age (range, M, SD)		20–75 (M = 47.2, SD = 12.1)
Location (n,%)	United Kingdom	226 (40%)
	United States of America	202 (36%)
	Australia	35 (6%)
	Other	102 (18%)
Years diagnosed (range, M, SD)		<1 – 44 (M = 10.2, SD = 9.1)
Self-reported MS type (n, %)	Relapse remitting	400, (71%),
	Primary progressive	50 (9%)
	Secondary progressive	84 (15%)
	Clinically Isolated syndrome	9 (1%)
	Unsure	22 (4%)

therefore 40% as there were 228 pwMS who had not accessed PPS previously, but currently want it.

Out of the whole sample, 497 pwMS wanted PPS (88%) regardless of whether they had previously accessed PPS or not.

With reference to specific types of PPS, the most frequently accessed type was counselling, accessed by 29% ($n = 165$) of the whole sample. The next most accessed types of PPS were mindfulness-based therapies (19%, $n = 109$) and Cognitive Behavioural Therapy (CBT) (19%, $n = 107$), followed by Cognitive Therapy (CT) (13%, $n = 72$), Behavioural Therapy (BT) (13%, $n = 72$), and self-management programmes (SM) (11%, $n = 63$), with other forms of PPS being less common (see Fig. 1). Only 5% of participants reported that they didn't know what type of PPS they accessed.

3.2. PPS types: patterns and combinations accessed

59% of those who accessed PPS ($n = 302$) accessed more than one type ($n = 174$). 20% ($n = 59$) accessed two types of PPS and 39% accessed more than two ($n = 115$). In fact, within the latter group, 14% ($n = 40$) accessed 3 PPS types, 7% ($n = 22$) accessed 4 types, 6% ($n = 19$) accessed 5 types. The remaining 34 participants (12%) accessed 6 or more PPS types. The maximum types of PPS accessed was 11 by 1 participant.

A one-way ANOVA showed that the more types of PPS pwMS accessed, the more helpful (rated out of ten) they found it, $F(2, 296) = 42.58, p < .001$. Those who accessed three or more types rated helpfulness of PPS as significantly more helpful ($M = 8.41, SD = 1.95$) than those who accessed only 2 ($M = 6.31, SD = 2.88$) or only 1 ($M = 4.92, SD = 3.62$). Those who accessed 2 rated PPS as significantly more helpful than those who accessed only 1 also ($p < .05$).

The various combinations of different types of PPS accessed by pwMS can be seen in Table 2. The most common combination of therapy access was counselling with mindfulness-based therapies, or CBT, a combination accessed by 26% ($n = 79$) and 22% ($n = 68$) respectively.

3.3. PPS types: Predictors of access

When examining predictors of PPS access, a multiple regression showed that MS and demographic variables (MS type, time since diagnosis, level of symptom bother, impact of MS on ability to sustain employment, living arrangements, age and gender) predicted whether PPS was accessed or not, $F(11, 564) = 6.35, p < .001$, and number of types of PPS accessed, $F(11, 564) = 5.34, p > .05$. Level of bother from

psychological symptoms and fatigue were the significant predictors in these models ($p < .05$) where the more bothered people were by these MS symptoms, the more likely they were to access PPS as well as access more types.

3.4. PPS types: Understanding patient preferences and motivations

The vast majority of participants (88%, $n = 497$) wanted PPS. Only 12% ($n = 68$) did not want PPS as they were content with the support they accessed from non-professional sources. Of those who would like PPS, 93% selected more than one type ($n = 462$) with the majority (60%) selecting more than 5 different types ($n = 298$). Of those who would like PPS, other than the 55 people (11%) who said they were not sure what type, only 35 people (7%) selected only one type. In particular, self-management programs showed the largest preference by 62% of participants ($n = 349$), as well as counselling selected by 60% ($n = 341$) and 54% would like mindfulness-based therapies ($n = 307$). Fig. 1 highlights patient preferences for each type of PPS.

In response to an open text question that asked why they would like their chosen selection of PPS, 21 people (4%) said they 'don't know' what they need and 46 people (9%) said they were willing to try anything and/or everything because 'everyone needs something' or 'because it has been a challenging part of my life, I'm willing to accept help from all the sources listed' and that 'as much support as possible would be beneficial'.

Only 33 people (7%) referred to a specific type of PPS preferred citing their reasons, such as 'self-management scheme would allow me to dip into it as and when I wanted', 'mindfulness and guided imagery for pain' and 'behavioural therapies to keep myself emotionally strong and grounded in the belief in ones self-worth regardless of disease progression'.

Instead of stating why they would like a certain type of PPS, the majority of participants responded explaining why they would like professional mental health support more generally. In these cases, there were three types of responses. There were those who felt they were in imminent need ($n = 88, 18%$) - 'its needed right now' due to 'currently having a relapse', being 'still in the discovery phase', 'at a low point' or 'struggling to deal with the MS', 'feeling trapped in the negatives', or not being able to 'accept my situation'.

The remaining participants didn't state any immediate pressing need but felt that this type of support would be useful to garner the skills to be able to cope better during periods of difficulty in the anticipation and understanding that MS is a continually changing and therefore such skills would likely be needed at some point in the future ($n = 116, 23%$). 'The more education and understanding I have, the better equipped I will be to

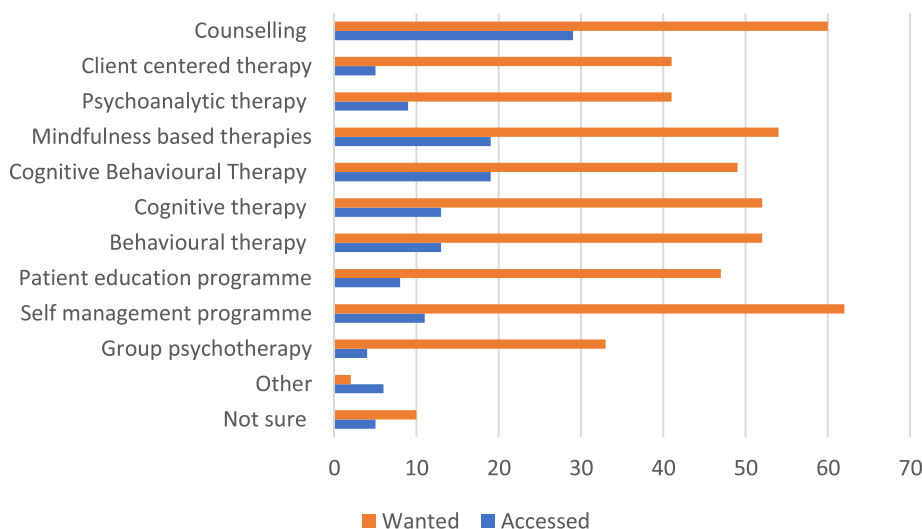


Fig. 1. Types of psychotherapy and professional psychological support (PPS) accessed, compared to PPS types wanted (percentages*). *participants could select multiple types of PPS.

Table 2
Different types of PPS of accessed according to number of PwMS.

	Couns (n = 165)	CCT (n = 31)	PA (n = 50)	MBT (n = 109)	CBT (n = 108)	CT (n = 70)	BT (n = 71)	PE (n = 46)	SM (n = 63)	Group (n = 22)	Other (n = 38)	Unsure (n = 30)
Couns	x	23	40	79	68	54	61	36	48	17	6	5
CCT	23	X	14	19	17	13	15	9	14	7	3	1
PA	40	14	x	29	27	23	23	13	20	10	3	2
MBT	79	19	29	x	58	48	49	26	37	16	5	1
CBT	68	17	27	58	x	43	45	24	35	15	4	2
CT	54	13	23	48	43	x	41	17	24	13	3	1
BT	61	15	23	49	45	41	x	24	30	15	3	1
PE	36	9	13	26	24	17	24	x	33	10	4	1
SM	48	14	20	37	35	24	30	33	x	11	4	2
Group	17	7	10	16	15	13	15	10	11	x	3	1
Other	6	3	3	5	4	3	3	4	4	3	x	1
Unsure	5	1	2	1	2	1	1	1	2	1	1	x
Sole therapy	37	3	2	7	18	1	4	1	2	2	26	22

*n in brackets.

Couns = counselling; CCT = client centred therapy, existential therapy, gestalt therapy; PA = psychoanalytic therapy; MBT = mindfulness-based therapy; CBT = Cognitive Behavioural Therapy; CT = cognitive therapy; BT = behavioural therapy; PE = patient education program; SM = self-management program; Group = group psychotherapy (focussed on managing relationships, such as family therapy).

Sole therapy = accessed alone with no other therapy.

take on all these challenges’ and therefore these seeking psychological support from mental health professionals who can ‘listen, question, offer some new insights or perspective and advices’ and ‘tie together practical help, emotional support and forward planning, all from someone who has a good knowledge of the process’ ‘is a way of taking back control’ by ‘learning how to navigate this condition’ because ‘symptoms are going to change over time’ and ‘there are always reasons to learn how to address those changes’.

Finally, there were also those who felt this type of support would be helpful to maintain or improve mental and overall wellbeing both in terms of living with MS itself as well as the impact it has more broadly on other aspects of life (n = 177, 37%). This group of people were looking for PPS as a means to ‘work on developing my maximum potential now that my mental health is stable’ because ‘you don’t often realise the impact it has on relationships and the mental wear it has on yourself over time’ so ‘there is always room to improve’ enabling pwMS to ‘continue to move forward in a positive way with MS’ where ‘MS has least impact on my life’.

3.5. PPS format: Accessed vs wanted

The format of accessed and wanted PPS is illustrated in Fig. 2. PPS

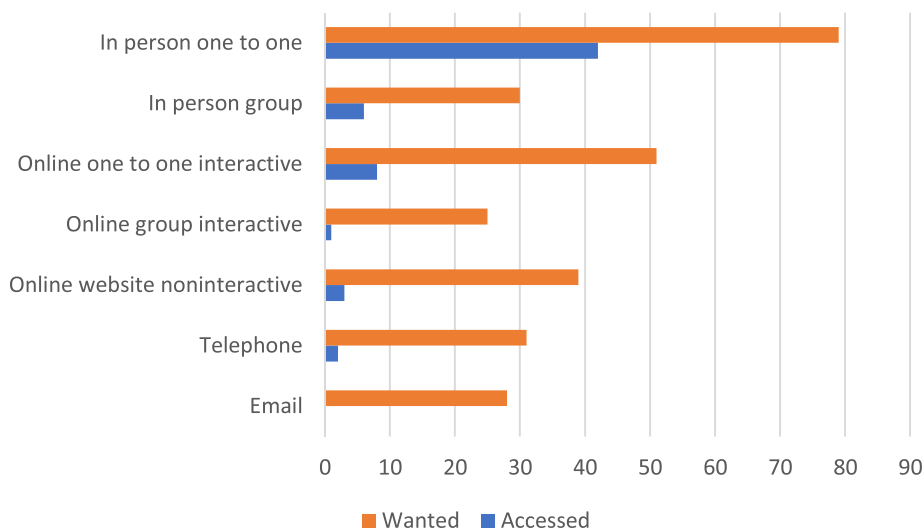


Fig. 2. Format of PPS delivery of psychotherapy and professional psychological support (PPS) successfully accessed, compared to PPS formats wanted (percentages*).

*participants could select multiple types.

4. Discussion

This study sought to understand the types of psychotherapy and professional psychological support (PPS) accessed by pwMS in the real world and to examine patterns of accessing different types of PPS. Additionally, we compared this with pwMS's preferences regarding PPS. Our novel approach where we asked the same cohort of pwMS to report on the different types of PPS they have accessed throughout their MS journey provides a deeper understanding of patterns of access and preferences with regards to PPS.

We found that most pwMS wanted PPS as a proactive approach to their psychological wellbeing. Less wanted it in response to an immediate pressing mental health concern. This signals the need for PPS that uses a proactive approach to psychological wellbeing to be provided early on in pwMS's diagnosis; a time when poorer coping skills have been linked to poorer adjustment (Lode et al., 2009). A proactive approach used in PPS would promote the process of enabling pwMS to feel prepared by equipping them with the skills to psychologically manage a chronic neurological condition as a means to prevent psychological symptoms that are commonly linked with maladaptive coping styles (Grech et al., 2018). Considering the reasons for desire to access PPS in a large proportion of our sample this provides a new perspective on how best to provide PPS to pwMS that better meets their needs. Health services for pwMS that take a proactive approach to mental health early on could help to overcome the current challenges noted in findings that state a lack of sufficient provision of PPS to pwMS (Kinyanjui et al., 2018, Ponzio et al., 2015), particularly for those with self-reported mental health concerns (Mindén et al., 2013).

In our unique sample with just over 50% having successfully accessing some form of PPS, and with some accessing up to 11 types of PPS, we found that higher levels of both from fatigue and psychological symptoms were the strongest predictors of accessing multiple types of PPS. Previous research has posited that fatigue and psychological symptoms in pwMS are particularly intrusive in daily life (Cowan et al., 2020). This may explain why pwMS with these symptoms in particular are seeking more PPS, especially when both from these symptoms in particular reaches a level that cannot be managed with support from other sources such as friends and family, MS peers, MS nurses and MS charities and organisations (Morris-Bankole and Ho, 2022). It is therefore of little surprise that higher levels of fatigue in pwMS has been linked to lower health related quality of life and having less friends in social networks (Eizaguirre et al., 2020). Similarly, depression and psychological distress have been found to be amongst factors that have the strongest impact on subjective well-being in pwMS (Yalachkov et al., 2019).

We examined the types of PPS pwMS had received and found that approximately half the sample had successfully accessed the PPS they sought. Counselling, mindfulness-based therapies and CBT were the most common types of PPS accessed. Over half of those who accessed PPS had accessed at least two different types. The majority of these accessed a mixture of counselling and CBT and/or mindfulness-based therapies. This may simply be a result of accessing what is available. It also suggests that pwMS are accessing more than one type of PPS as they navigate life with MS to satisfy different and changing psychological needs (Lexell et al., 2009) such as getting emotional support from less directive therapies such counselling, and practical skills from approaches such as CBT and mindfulness-based therapies that may be more difficult to target with a single therapeutic approach. Alternatively, perhaps pwMS choose to try out different types until they found something deemed suitable. Either explanation is supported by our finding that the more types of PPS pwMS access, the more helpful they report PPS support overall. Further qualitative research could seek to understand more clearly what drives pwMS to access different types of PPS to develop a better understand the role of different types of PPS in the illness trajectory.

Our results showed that the majority of pwMS are open to accepting

any type of PPS. This may suggest a number of things. It may be that pwMS do not know what the different types of PPS entail but have the need for PPS and/or are open to trying anything so would accept any type. Given the responses when asked why they would like the types selected (current need, to learn skills to cope with MS as and when needed in the future, and to boost psychological wellbeing), perhaps the most likely explanation is pwMS's desire to take a more proactive approach to managing their mental health. Our finding that an approach that incorporates a self-management element is amongst the most wanted type of PPS supports this conclusion also.

Previous research found that being happy with support received from other sources is the most common reason for not accessing PPS (Morris-Bankole and Ho, 2022). However, in our present study, we found that the majority of people still want PPS too and that 40% of those who did not access PPS previously, want it now. This suggests that participants have been managing their mental health adequately with support from other sources but would also like support from another source (in this case, mental health professionals) as a means of preparation through skill building to self-manage as and when needed.

We also found that programmes with a self-management component were the most desired type of PPS, yet were only the sixth most accessed type of PPS. This also suggests that a possible reason for the discrepancy between the number of pwMS accessing PPS and desiring to access may also be due to the lack of appropriate PPS available to meet the specific needs of this population. In the present study we found that pwMS want PPS to provide a proactive means to preserve and boost psychological well-being or learn skills to manage future difficulties as and when they arise. We also found that aside from being happy with support received from other sources and not knowing what's available (Morris-Bankole and Ho (2022), reasons for not accessing PPS were due to perceived lack of understanding and experience of mental health professionals in providing suitable psychological support to pwMS due to their lack of knowledge, understanding and experience of the condition. This also provides evidence suggest that the lack of understanding of the experience of MS may be hindering the delivery of appropriate PPS in this population and therefore may be contributing to the discrepancy between PPS accessed and wanted.

Our data show a general openness to accessing different types of PPS and also to using online non-interactive (self-guided) means, particularly when in-person services were disrupted (Morris-Bankole and Ho, 2021). With a growing trend towards delivery of psychological interventions online (Tallner et al., 2016), this allows for patient needs to be accommodated due to flexibility in access, something noted to be of particular importance to younger and more mildly affected groups (McCabe et al., 2015). Data from the present study was collected during the COVID lockdown period which prompted alternative methods of access to support (online, phone and email), including PPS. This may be, in part, be what has promoted increasing openness to accepting these alternative approaches to care.

Our finding that the majority of people are open to accessing different types of PPS in different ways again highlights the finding that the majority of pwMS would like to have access to PPS and that the need is there but is not being met for a large proportion of pwMS. This has implications for the delivery of PPS to pwMS. Firstly, it might be beneficial to provide PPS that integrates multiple psychotherapeutic approaches because we found that pwMS are looking for PPS that provides them with different tools to deal with various types of difficulties as and when they arise. Furthermore, making available a wider array of PPS and informing pwMS of the different approaches and how they work, could help empower pwMS in managing their mental health. Our finding that PPS is wanted considerably more than it is being accessed suggests the need for more services to be made easily accessible to all pwMS, not just those presenting with flagrant and pressing mental health difficulties. This would help to facilitate the much needed proactive approach to managing psychological wellbeing. Findings from this study highlight the importance of closer collaboration within the

broader care team relevant to pwMS and call for better service planning and provisioning by tailoring PPS for pwMS's needs and preferences to better cater for their psychological wellbeing.

While the use of self-report was appropriate for the aim of the study and allowed for the patient voice to be made clear, it is recognized that all self-report data is naturally limited to presenting the patient's perspective only. However, engagement with PPS is a personal endeavour, and further qualitative exploration would be appropriate on this topic allowing for a deeper exploration into the present findings.

5. Conclusion

This novel set of findings that uncovers the current psychotherapeutic landscape in MS shows that to truly meet the psychological needs of pwMS, PPS must be proactive to preserve psychological wellbeing, rather than being purely reactive to moments of crisis. PwMS want to take a preventative approach to maintain good mental health and need much more PPS to help equip them than what they are able to currently access.

This is a clear call for more provision of psychological support early on in neurological conditions such as MS. Patients want to focus on actively maintaining and preserving psychological wellbeing before any major mental health challenges that may come their way in the context of their underlying and long-term condition.

CRedit authorship contribution statement

Hannah Morris-Bankole: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Data curation, Project administration, Writing – original draft, Writing – review & editing, Visualization. **Aileen.K. Ho:** Conceptualization, Methodology, Visualization, Formal analysis, Investigation, Writing – original draft, Writing – review & editing, Supervision.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

Data is available from corresponding author on reasonable request.

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