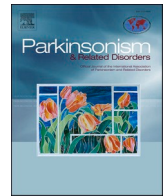




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Short communication

Support needs of people with Multiple System Atrophy

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ABSTRACT

Background: Multiple system atrophy (MSA) is a neurodegenerative disease with presentations including parkinsonism, autonomic disturbances, gait impairment and mood disorders. The progressive nature of MSA results in a significant deterioration in quality of life for patients.

Objectives: To investigate the needs of people with MSA (PwMSA) in the United Kingdom (UK) and the support provided to them.

Methods: A survey of members of the UK's MSA Trust including PwMSA and former carers explored questions on the physical, emotional, personal and financial impact of MSA and on support received.

Results: There were 284 valid responses from PwMSA and 371 responses from former carers. Difficulties with movement were universally experienced by PwMSA. The majority of former carers reported these as difficult or very difficult to manage (90 %), followed by autonomic problems (85 %) and breathing, speech or swallowing problems (81 %). PwMSA also reported fatigue (96 %), mood disorders (80 %) and social isolation (82 %). 41 % of former carers felt that the emotional needs of PwMSA had not been met. Many also reported inadequately covered financial needs (48 %). Equipment used most commonly included mobility equipment (90 %). The majority received support from neurologists (95 %) and GPs (92 %), but few from palliative care or mental health professionals. Satisfaction was highest for support from palliative services (95 %) and specialist nurses (91 %).
Conclusion: This survey demonstrates the high burden of MSA across various aspects of life for PwMSA. It suggests that whilst there is good provision of neurology services and physical equipment, there is a need to improve support for their emotional and social needs.

1. Introduction

Multiple system atrophy (MSA) is a neurodegenerative disease with presentations including parkinsonism, autonomic disturbances such as orthostatic hypotension, gastrointestinal and urinary dysfunction, and ataxia [1]. Rates of depression and anxiety are high [2]. The prognosis for people with MSA (PwMSA) is poor, with a mean survival of 8–10 years [3]. Unfortunately, there are currently no disease-modifying therapies to slow down or reverse progression of the disease, and treatment focuses on symptom management. Unsurprisingly, this progressive neurodegenerative condition causes significant deterioration in patients' quality of life [4] and increases their reliance on support from caregivers and health and social care services.

Given the wide variety of symptoms associated with MSA, the functional outcomes and impact on patients are considerable and affect

multiple aspects of their lives. This highlights the need for a holistic, patient-focused approach to addressing the different needs of PwMSA.

This study aimed to investigate the experience of MSA by PwMSA and former carers in the UK, particularly the physical and mental health challenges faced by PwMSA and support available for them.

2. Methods

We analysed answers from a survey, which consisted of a questionnaire sent to PwMSA and a modified questionnaire sent to former carers, conducted from 24/06/2019 to 23/08/2019 amongst members of the MSA Trust. The survey could be completed anonymously online or on paper.

The wider survey consisted of 52 questions. It aimed to investigate the experiences of patients and of former carers when they had been

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caring for PwMSA in order to improve gaps in care.

This current study focused on the first 37 questions in the survey including questions on the physical, emotional, social and financial impact of MSA and support available (Supplementary Information).

2.1. Data analysis

The responses to questions were reported using percentages and graphically illustrated using Microsoft Excel.

2.2. Ethical considerations

As the primary aim of the survey was collection of data for the MSA Trust on the needs of people with MSA to plan support and services for those living with MSA amongst its members, no ethics approval was required. No personal data were shared with the researchers. The survey included information on this purpose and use of the data and stated "By completing this questionnaire, you are giving your consent for the information you provide to be used for the above purpose."

3. Results

3.1. Participants/demographics

A total of 284 responses (195 online and 89 paper responses) out of 1213 individuals who were contacted were received, representing a response rate of 23 %. Of the 261 respondents who indicated their age band and gender, 66 % were aged 65 years and above, and 47 % were female and 53 % male. Forty-one percent PwMSA reported a disease duration of between 0 and 5 years, 42 % of 6–10 years, 10 % of 11–15 years, 3 % 16–20 years and 4 % over 20 years.

There were also a total of 371 responses (201 online responses and 170 paper responses) out of 873 former carers who were contacted. 75 % of these respondents were aged over 65 years, and 28 % were male and 71 % female. 1 % of respondents preferred not to disclose their gender.

3.2. Symptoms experienced by PwMSA

All respondents reported that they had difficulties in moving such as problems with balance, coordination, tremor, slowness or stiffness, 97 % had experienced autonomic problems such as bladder or bowel problems, temperature control, sexual dysfunction or blood pressure problems, and 96 % reported difficulty with breathing, speech or swallowing. Pain was reported by 72 % of PwMSA respondents. Sleep disorders had occurred in 80 %, and difficulty concentrating in 78 %. There was no difference in the occurrence of these symptoms between male and female PwMSA.

3.3. Physical challenges former carers of PwMSA found the most difficult to manage

Carers of PwMSA reported the physical challenges they found most difficult to help with were mobility issues, autonomic problems and breathing, speech and swallowing difficulties, which 90 %, 85 % and 81 % of respondents indicated they found "very difficult" or "difficult" to manage, respectively.

3.4. Equipment to assist with walking used by PwMSA

60 % of PwMSA reported using a wheelchair. Other walking aids used were a rollator (29 %), walker (31 %), walking stick (30 %) or other aids (13 %), and 30 % relied on their partner/carer to help them with walking. The vast majority of carers (92 %) reported that the PwMSA had seen a health care professional to obtain assistive equipment. The most common useful assistive equipment reported by carers in caring for PwMSA were mobility aids, particularly wheelchairs, walkers and

walking sticks.

3.5. Other assistive equipment

Among non-mobility aids, 27 % of patients used a urinary catheter and 15 % used communication aids. 9 % reported ventilatory support, 5 % were PEG-fed and 1 % had a tracheostomy.

3.6. Mental health challenges faced by PwMSA

The most commonly reported issues were fatigue (96 %), low mood/depression (80 %), anxiety (70 %) and stress (75 %). The rate of reported anxiety was higher in women than men (75.5 vs 62.9 %, $p = 0.048$) and the rate of reported depression tended to be higher in women (74.8 vs 85.3 %, $p = 0.054$). Whilst 53 % of patients felt that their emotional needs were met at least to some extent, 30 % did not feel they were met at all. Similarly, 41 % of former carers felt that the emotional needs of PwMSA had not been met.

3.7. Interpersonal challenges faced by PwMSA

Of the PwMSA who responded to questions on interpersonal challenges faced, 82 % reported feeling more isolated socially and 46% reported their relationship with friends had deteriorated; 31 % felt their personal relationship with their partner had become worse and 24 % felt their family relationships had become worse, but 13, 17 and 18% felt that their relationship with their friends, partner and family, respectively, had improved.

In addition, 86 % felt their sex life had been affected. 93 % of these did not receive treatment or support for this. The 7 % who did receive support received it in the form of referral to specialist services, counselling and medication. However, 60 % felt that the support they received did not help. It is noted that the number of responses for questions in this section were small with a large number of missing or "don't know" responses (see Supplementary Information).

3.8. Support received by PwMSA from healthcare professionals

Of the patients who responded to questions on support received from healthcare professionals, the three healthcare professionals from whom the highest proportion of PwMSA received support were neurologist/PD specialist (95 %), own GP (92 %) and occupational therapist (79 %). In contrast, a much smaller percentage of those who responded saw a counsellor/psychiatric team (23 %), dietician (31 %) or palliative care professional (32 %). Of note, satisfaction was overall positive across professional groups. The healthcare professionals with the highest proportion of responses that reported receiving satisfactory support ("excellent", "good" and "adequate" responses) were palliative care/hospice teams (95 %), speech and language teams (91 %) and MSA Trust nurse specialists (91 %) (Fig. 1).

Similar to responses from PwMSA, former carers of PwMSA who received support reported receiving satisfactory support ("excellent", "good" and "adequate" responses) from MSA trust nurses (94 %), palliative care/hospice teams (89 %) and community matron/district nurse (90 %) (Fig. 2).

3.9. Helpfulness of other therapies reported by PwMSA

In addition to the healthcare professionals' treatments above, other therapies that PwMSA rated highest (defined as "excellent", "good" and "adequate" responses) in helping with MSA were massage (93 %) and exercise (88 %).

Not many PwMSA reported having received group and individual counselling (26 %) or psychological therapy. However, among those who did, a substantial number of patients (76 % and 73 % respectively) found them helpful.

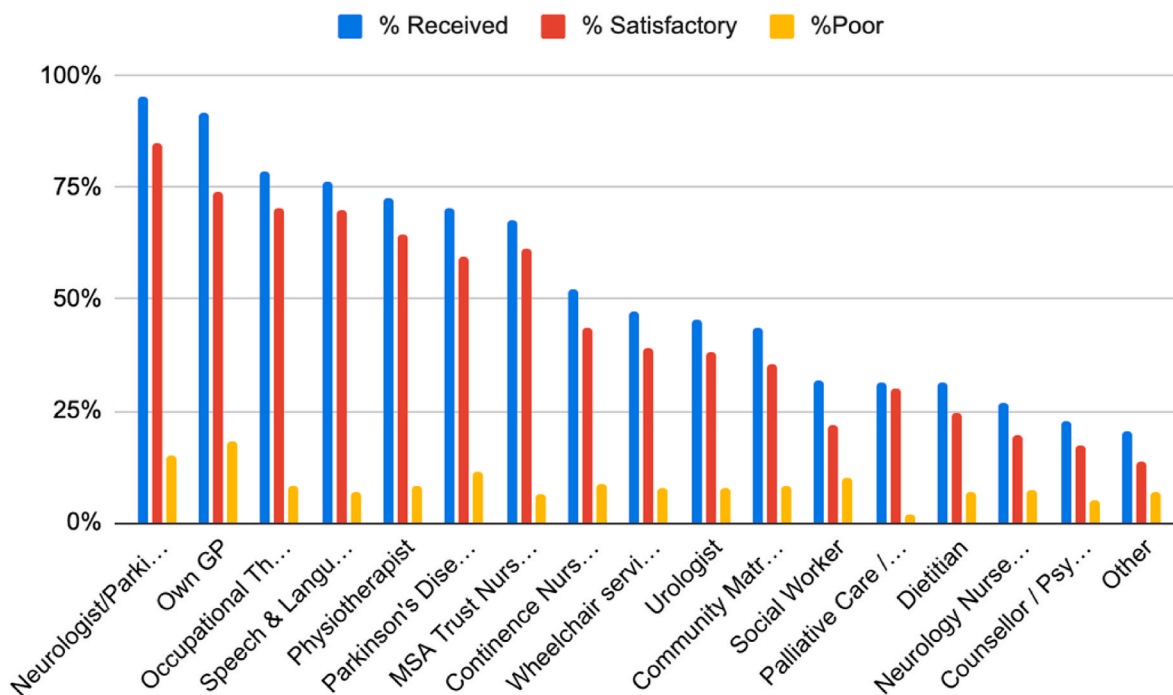


Fig. 1. Proportion of people with MSA who received support (blue) from various healthcare professionals and the proportion of people with MSA who received satisfactory support (red) from them. Satisfactory responses included 'excellent', 'good' and 'adequate' responses. (For interpretation of the references to colour in this figure legend, the reader is referred to the Web version of this article.)

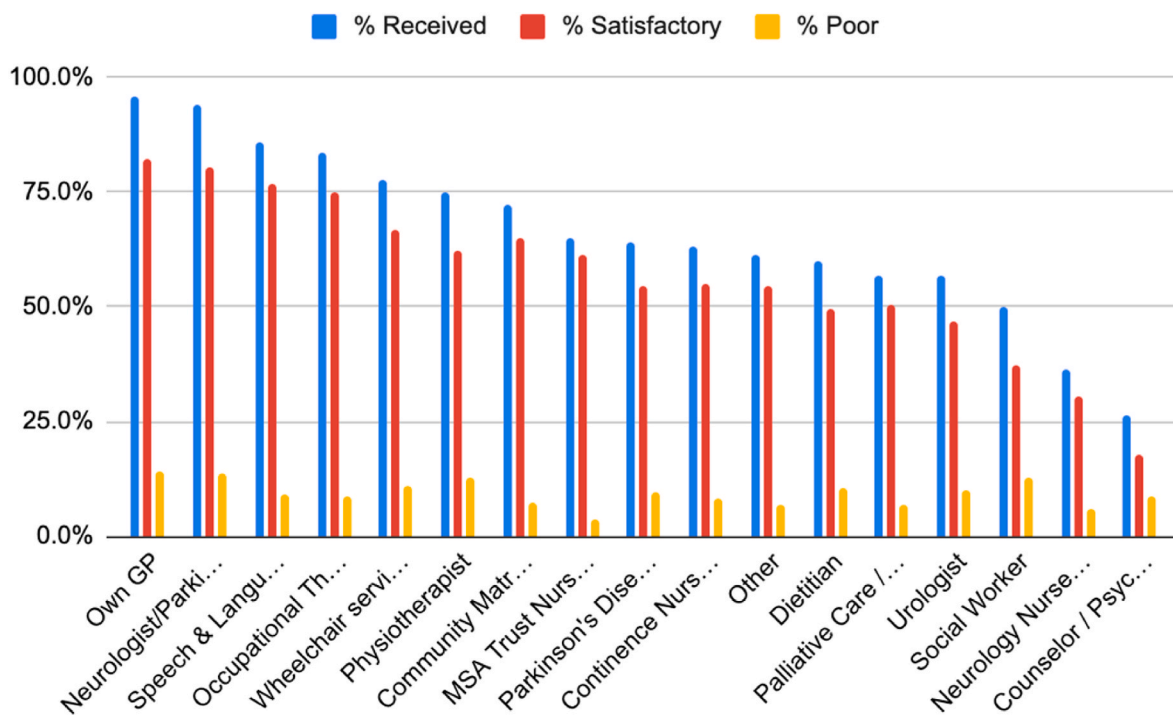


Fig. 2. Proportion of former carers who report people with MSA receiving support (blue) from different healthcare professionals and those who received satisfactory support (red) from them. Satisfactory responses were defined as 'excellent', 'good' and 'adequate' responses. (For interpretation of the references to colour in this figure legend, the reader is referred to the Web version of this article.)

3.10. Financial impact on people with MSA

Only 13 % of PwMSA were in employment at the time of the survey, with 8 % of patients working reduced hours. 12 % of patients reportedly did not receive benefits. Of note, whilst 52 % of patients who answered

felt they had no financial issues, 5% and 43 %, respectively, felt their financial needs were not at all or only partly met. Similarly, 43 % of former carers reported their financial needs not having been fully met, among whom 6 % did not feel their financial needs were met at all, and 28% reported long-lasting effects on their financial circumstances.

4. Discussion

4.1. Support for the management of challenges faced by PwMSA

In this survey of PwMSA and former carers of PwMSA, mobility issues, breathing, speech and swallowing difficulties and autonomic problems were the most difficult symptoms to manage. Challenges with pain and sleep problems were also common. This is in keeping with findings from previous studies of the symptoms commonly experienced by people with MSA [5,6]. The most useful equipments reported by both PwMSA and their former carers were mobility aids, with a substantial proportion also using aids for breathing and swallowing such as ventilatory support and PEG.

The majority of respondents also reported emotional challenges. Previous studies have highlighted the prevalence of depressive symptoms and their impact on satisfaction in life [7]. Although it is likely that the disease process contributes to these high rates of depression, several psychological, social and financial factors may also contribute. It is noteworthy that the majority of PwMSA reported an impact on social relationships and interactions with others, although some also reported an improvement in social relationships. At the same time, whilst most reported that they had received support from healthcare professionals for their physical needs, there was little support for their emotional needs.

The most commonly helpful therapies received were occupational, speech and language and physiotherapy and day hospice care, while the most commonly rated helpful complementary therapies received were exercise and massage. Previous studies have supported the benefits of physiotherapy and occupational therapy in MSA and Parkinson's patients [8]. Not many patients reported having received group and individual counselling or psychological therapy. Among those who did, the majority found them helpful. Of note, there are no studies on the benefit of these therapies on people with MSA. However, early studies have reported the preliminary benefits of psychological therapy in managing psychological issues faced by patients with other neurodegenerative conditions such as Parkinson's disease (PD) and multiple sclerosis (MS) [9]. With the growing interest in the use of complementary therapies in managing symptoms in movement disorders, some studies have suggested that complementary therapies such as exercise and tai chi have helped manage motor symptoms in people with PD [10]. Music therapy has been reported to have positive effects in managing motor symptoms as well as supporting the emotional aspect of people with PD. On the other hand, less evidence is available for complementary therapies such as meditation [10]. The reported advantages of therapies and complementary therapies in the management of neurodegenerative diseases suggests that adopting a holistic, multi-disciplinary approach may be of benefit in the management of PwMSA.

4.2. Potential for palliative care support

In this survey study, a substantial proportion of both PwMSA and their former carers reported receiving excellent support from the palliative care team and MSA trust nurses they engaged with. This reinforces the above findings and the value of palliative care in the management of MSA. Research on palliative care in the management of MSA is growing but limited. However, studies on the value of palliative care in the management of other neurodegenerative diseases have reported improvements in quality of life and physical symptoms in patients [11]. Providing access to palliative care may therefore be helpful in improving the management of PwMSA. Furthermore, given the high satisfaction rates with MSA trust nurses in both patients and caregivers, providing access to specialized centres with dedicated nurses to support patients living with the disease and coordinate care is likely to have a significant impact on PwMSA and their carers and help improve satisfaction with care.

4.3. Financial support

The majority of PwMSA were not employed at the time of the study, whether they had been retired at the time of diagnosis or had been required to stop working due to their disease progression. 48 % of PwMSA felt that their financial needs were not being fully met in managing their disease. This was also reflected in the responses from former carers of PwMSA. Of note, over a quarter of former carers reported long-lasting effects on their financial situation from caring for their PwMSA. Previous studies have also reported the financial burden and costs of neurodegenerative diseases, which extend beyond medical costs [12].

4.4. Limitations

This study utilised data gathered from a questionnaire distributed by the MSA Trust UK, and it is likely that unmet needs are higher in patients who are not members of this patient support organisation as they may have access to fewer resources. Furthermore, not all questions were answered by every participant, and questions with missing responses may have affected the accuracy and strength of the data collected. Full details on the proportion of missing responses for each question are reported in the Supplemental Material. In the caregiver survey, data were collected from former rather than current caregivers in order to capture the experiences of the population even at the latest stage of the disease, including at the end of life. However, these responses may have been biased in the context of the PwMSA having already died or being in advanced stages of disease requiring admission to a nursing home. Additional information from current carers on their own perspective may have provided further insight into their experiences at different stages of the disease. Finally, the survey provided self-reported information from PwMSA and former carers and therefore a subjective experience. Information from health records and examination was not available and would provide complementary information.

5. Conclusion

The needs of both PwMSA and their former carers extend beyond physical symptom management, involving various aspects of their lives. This study highlights discrepancies between needs identified by patients and carers and the services to meet these needs. A holistic approach such as through palliative care, including psychological and complementary therapies, may best address the needs of this population and improve patient welfare and carer burden.

CRediT authorship contribution statement

Julia LY. Cheong: Data curation, Project administration, Writing – original draft. **Zhao HK. Goh:** Data curation, Project administration, Writing – review & editing. **Anette Schrag:** Conceptualization, Formal analysis, Methodology, Supervision, Writing – review & editing.

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.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.parkreldis.2024.106019>.

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