

Title:

Uptake of and Factors Associated with Advance Care Planning in People with Multiple System Atrophy: Results of the Largest Known Survey of People with Multiple System Atrophy

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Background

There is growing evidence that advance care planning (ACP) can improve end-of-life care in parkinsonian disorders (PD) such as Multiple System Atrophy (MSA), a rare and incurable atypical parkinsonian disorder characterised by a complex and progressive symptomology [1]. ACP offers patients the opportunity to record their values and preferences for future medical care. ACP comprises the stages of thinking about values and wishes; discussions with family, friends and healthcare professionals (HCPs); and completing formal ACP documentation [2]. ACP is associated with positive outcomes such as improving the quality of care [3].

One barrier to increasing the uptake of ACP is the paucity of research on the proportion of patients who engage with ACP, and the factors associated with its uptake of [4]. To address these research gaps, this study utilised data from the largest survey completed by MSA patients in the UK to: (1) identify what proportion of people with MSA

engage in the different stages of ACP and, (2) identify a range of factors identified in the literature and recorded in the MSA survey to test whether they are associated with the three stages of ACP.

Method

This was a correlational secondary data analysis using data from the 2019 MSA Needs Survey ($N = 284$). Participants provided informed consent, undertaken in line with relevant requirements of the Data Protection Act 2018 and General Data Protection Regulation.

Three outcome variables were collected encompassing the three discrete stages of ACP [2]: *thinking* about end-of-life care; *discussing* end-of-life care with health care professionals; and *completing* or considering a health and welfare Lasting Power of Attorney (LPA). We investigated potential correlations between our outcome variables and nine factors previously identified within the literature as associated with ACP: level of dependence, the impact of MSA on quality of life, length of time with MSA, presence of a care plan, self-rating of support from a primary care physician, receipt of hospice day care, and demographic factors of age, gender and relationship status

Chi-square tests and Cramér's V were used to analyse the association and effect size, respectively, between categorical and ordinal variables. Fisher's exact test statistic was used in place of chi-square when more than 20% of expected counts were less than 5. Spearman's Rho was used to analyse data between two ordinal variables, with effect size determined by the size of the correlation coefficient in these cases.

As this was an exploratory analysis with no prespecified hypothesis, no corrections for multiple testing were performed to ensure that type 2 errors were minimised in this new area of research.

Results

Descriptive statistics showed that most respondents (76%) had thought fully or to some extent about end-of-life care. Fifty-four percent had completed and a further 21% had considered completing a health and welfare LPA. Discussing end-of-life care with a healthcare professional (HCP) was the least common stage of ACP respondents engaged in (37%). Of those that had had this discussion, 86% found it helpful. Of those who had not had this discussion, 62% would like to.

The presence of a current care plan was weakly associated with *thinking* about end-of-life care (Cramér's $V = .19$), and moderately also with *discussing* end-of-life care with an HCP (Cramér's $V = .41$) but not having *completed* an LPA. Higher dependence level ($r_s = .30$) and a greater impact of MSA on quality of life ($r_s = .21$) were significantly correlated with *discussing* end-of-life care with an HCP, and with having *completed* a health and welfare LPA ($r_s = .18$ and $r_s = .22$ respectively). Length of time living with MSA ($r_s = .26$) and receiving day hospice care (Cramér's $V = .19$) were weakly associated with *discussing* end-of-life care with an HCP, and higher age ($r_s = .17$) was weakly positively correlated with having a health and

welfare LPA. There were no significant relationships of gender, relationship status and self-rating of support from a primary care physician with any of the three stages of ACP.

Discussion

Most MSA patients had thought about end-of-life care, with just over half completing a health and welfare LPA. Discussing end-of-life care with an HCP was the least commonly enacted stage of ACP, which is supported by wider research [5]. Of respondents who had not had this discussion with an HCP, 62% wanted to. This indicates an unmet need for end-of-life care discussions and possibly that patients or HCPs may not know how to initiate end-of-life care discussions. This finding has important implications, as HCPs being uninformed of patient wishes could result in the application of unwanted medical treatment at the end-of-life. Results indicate that many people have thought about their end-of-life care but not completed ACP documentation, possibly indicating that MSA patients do not have enough information about ACP.

Results for nine factors that have been previously associated with ACP stage differed for each ACP stage. Having a current care plan was associated with thinking about and discussing ACP with an HCP, suggesting that having a care plan encourages and enables ACP contemplation and discussion. Greater length of time with MSA, impact of MSA on quality of life, dependency and receiving day hospice care were correlated with discussing end-of-life care with an HCP and receiving day hospice care and length of time with MSA with completing a health and welfare LPA, suggesting that those with longer disease duration and more severely quality of life and independence are more likely to be willing or have the opportunity to discuss ACP wishes with healthcare providers, but only those with longer disease duration or having hospice care actually have these documented.

This study offers novel insights into ACP decision-making in MSA patients, and factors facilitating these. The survey respondents were majority white (98%) and may be more open to discussing the sensitive issues raised in the survey than non-responders, but the findings nevertheless indicate that providing a care plan and hospice care, particularly in those with advancing disease can facilitate ACP being discussed and documented.

List of Abbreviations

ACP Advance Care Planning

HCP Healthcare Professional

LPA Lasting Power of Attorney

MSA Multiple System Atrophy

PD Parkinson's Disease

Conflict of Interest Statement

The Authors declare that there is no conflict of interest.

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Authors' contributions

KF: Design, analysis, interpretation, drafting and revision.

CEB: Analysis and revisions.

AS: Design, interpretation and revisions.

JS: Design, interpretation and revisions.

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