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Supporting access to activities to enhance well-being and reduce social isolation in people living with motor neurone disease

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Abstract

Purpose: People living with Motor Neurone Disease (plwMND) have emphasised the importance of psychological support and well-being in helping them manage their condition. Social prescribing is a formal process of referring patients with largely socioeconomic and psychosocial issues to a link worker to co-design a plan to improve their health and well-being. Intervention involves supporting engagement in meaningful activities based within the individual's local community. This pilot project aimed to explore the application of social prescribing with plwMND.

Methods: A cohort of plwMND were supported by an occupational therapist and link worker to identify and access community-based activities. Qualitative interviews were completed post-intervention with the plwMND and the link workers. Findings were analysed using thematic analysis.

Results: A total of nine plwMND took part in this pilot service, and five plwMND and four link workers were interviewed. PlwMND valued participation and wanted to engage in community-based activities. Those with mild symptomatology were able to access activities and reported a positive impact on their well-being. Those with more complex needs, particularly reduced mobility, experienced significant barriers to participation. Barriers included transport, equipment provision, lack of company to support participation and lack of confidence using mobility aids in a community environment. Link workers valued joint working with an occupational therapist.

Conclusion: Social prescribing aims to address the health inequalities of those living with long-term conditions, although currently it likely excludes plwMND. Future work needs to quantitatively evaluate the effects of the service on the well-being of plwMND.

KEYWORDS

implementation, motor neurone disease, quality of life, social prescribing

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1 | INTRODUCTION

Motor neurone disease (MND) is a life shortening neurodegenerative disease affecting the motor neurones. Currently, there is no cure and death is nearly always linked to respiratory failure (Young et al., 2019). Prevalence rates for MND are reported to be around 3 cases per 100,000 people, and incidence increases with age, with the majority of people diagnosed at 47–63 years of age (Ando, Cousins, & Young, 2019).

Quality of life (QoL) in people living with MND (plwMND) is linked to high self-esteem and self-efficacy (Schlüter, Tennant, Mills, Diggle, & Young, 2018). The nature and range of both physical and psychological factors have been shown to influence the QoL of plwMND (Young et al., 2019). A scoping review by Harris et al. (2018) concluded that although psychological problems are well recognised in MND, high-quality intervention research is lacking.

Social prescribing could be one way of improving QoL (Pescheny, Randhawa, & Pappas, 2019). Social prescribing has been defined as a formal process of referring patients with largely socio-economic and psychosocial issues to a link worker, to co-design a plan to improve their health and well-being (Polley, Fleming, Anfilogoff, & Carpenter, 2017). The link worker facilitates engagement in meaningful activities often provided by voluntary and community sector organisations (The Kings Fund, 2017). Examples of social prescribing activities include volunteering, accessing educational courses, attending social or lunch clubs, and dance or art classes (Brandling & House, 2009). Social prescribing has seen growing momentum over the last few years. Earlier this year it was announced that 1,000 link workers would be employed across England to provide an additional resource in primary care teams by April 2021 (National Health Service England, 2019).

A review in 2015 highlighted a lack of good quality evidence to inform the commissioning of a social prescribing programme (The University of York Centre for Reviews & Dissemination, 2015). Specifically, most of the available evidence has been evaluations of pilot projects, with insufficient detail to judge effectiveness (The University of York Centre for Reviews & Dissemination, 2015). These findings have been further supported by subsequent systematic reviews, which concluded that the evidence base for social prescribing is very limited compared to the momentum to implement (Bickerdike, Booth, Wilson, Farley, & Wright, 2017; Pescheny et al., 2019; Polley et al., 2017).

Evidence on meaningful activities that improve mental well-being has focused predominately on the general population or on people living with long-term conditions (The Kings Fund, 2017). The Foresight project (Government Office for Science, 2008) outlined five actions to improve well-being. These were connect, be active, take notice, keep learning and give. The All-Party Parliamentary Group on Arts, Health, and Wellbeing (2017) reports an association between creative activities and self-reported subjective well-being in the general population. The use of music and singing in adults has demonstrated a positive effect on well-being (Daykin et al., 2018).

Effective interventions to address loneliness include physical activity, befriending schemes, skills training, and community-based group activities (Victor et al., 2018).

There is less research looking at the use of meaningful activities to improve well-being in people living with long-term neurological conditions (LTNC). Parkinson's disease has seen increasing interest in the use of exercise including dancing (Michels, Dubaz, Hornthal, & Bega, 2018; Shanahan, Morris, Bhriain, Volpe, & Clifford, 2017) and yoga (Ni, Mooney, & Signorile, 2016; Sharma, Robbins, Wagner, & Colgrove, 2015) to improve well-being in addition to physical health. A recent systematic review found mindfulness to be an effective intervention for improving well-being in people living with multiple sclerosis (Simpson et al., 2019). Well-being and dementia has been the most widely researched with evidence for the use of exercise (Junge, Knudsen, & Kristensen, 2018; Olsson, Lampic, Skovdahl, & Engström, 2013), creative activities (Windle et al., 2018), gardening (Gonzalez & Kirkevold, 2014; Hall, Mitchell, Webber, & Johnson, 2018) and music (Evans, Garabedian, & Bray, 2017; van der Steen et al., 2018) to improve self-worth, social interaction and QoL. There is limited published research available to determine which specific meaningful activities might enhance the well-being of plwMND. Studies by Ng, Talman, and Khan (2011) and Locock and Brown (2010) explored the benefits of peer support groups for plwMND. Peer support provided opportunity to exchange useful information or a sense of camaraderie, while for some people witnessing the progressive nature of MND was distressing and accessibility and limited frequency was seen as problematic, indicating that peer support groups were beneficial for some plwMND, but not all.

The aim of this pilot study was to assess the feasibility of identifying suitable activities that support psychological well-being and prevent the likelihood of social isolation for plwMND. Specifically, this study aimed to identify potential barriers and facilitators to the implementation of this intervention, from the perspectives of plwMND and social prescribing link workers.

2 | MATERIALS AND METHODS

2.1 | Participants and recruitment

Recruitment was carried out by the MND association visitors, public advisors, outpatient therapists, community therapists and council-based occupational therapists in two regions across the North West Coast of England. Participants had a confirmed diagnosis of MND. According to the Amyotrophic Lateral Sclerosis Functional Rating Scale ALSFRSR (Cedarbaum et al., 1999), a score below 30 indicates a moderate presentation of the disease and was used to inform inclusion. Exercise is known to be contraindicated with chronic symptomatology (Eidenberger & Nowotny, 2014). Participants with a score above 30 were considered and judged on a case-by-case basis, this was because wheelchair users or those with swallowing

or speech problems may have a score above 30, but could be capable of participation. PlwMND requiring respiratory support during the day were excluded as this could not be facilitated in a community setting.

The pilot was registered as a clinical service evaluation and approved by the Walton Centre NHS Foundation Trust clinical audit group prior to commencement. Participants were assessed to ensure they had capacity to participate and provided written informed consent prior to participation.

2.2 | Intervention

To ensure the provision of activities was based on the person's interests, the Modified Interest Checklist was used to initiate discussion and to aid choices-related interventions (Taylor & Kielhofner, 2017). Participants were supported to prioritise their choices, and issues around risk and barriers were explored. A plan was formulated and actions agreed. The level of intervention provided by the occupational therapist and link worker depended on the participants' choices and aspirations.

2.3 | Data collection

Interviews were carried out post-intervention with plwMND to gain feedback on the intervention, with link workers interviewed throughout the implementation project.

2.4 | Data analysis

Interview data were analysed using thematic analysis. Thematic analysis is a method of exploring, analysing and reporting patterns within themes and identified based on prevalence and/or keyness (Braun & Clarke, 2006).

2.5 | Public Involvement

Two former MND carers and a charity-based neurological conditions information and advice officer were involved in the concept, design, analysis and dissemination. All attended regular team meetings and workshops, hosted by the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care North West Coast (NIHR CLAHRC NWC). Advisers were reimbursed according to NIHR INVOLVE (2015).

3 | RESULTS

A total of 13 people participated in this pilot implementation study (nine plwMND, four link workers). Five plwMND, two male and three

female participants agreed to participate in the interviews for the evaluation (with four declining to be interviewed due to changes in their condition and others not wanting to receive support). Participants were on average 56 years old, with an age range 40–79. The mean time since formal diagnosis to referral to the project was 13.6 months (4–28 months). Four link workers participated in a group interview; all were female and had backgrounds in practical support services such as benefits advice. The social prescribing service is a Primary Care mental health service for plwMND aged 16 + who are registered with a local GP. Across the nine interviews, six themes were identified, some which were pertinent only to plwMND and others to link workers.

3.1 | Participation

PlwMND were asked why they wanted to participate in the project and how they felt about their levels of activity at the time of recruitment. Those with mild symptomology referenced finishing full-time employment and wanting to find something that would support this transition. Activities were something to focus on, helped to prevent time feeling wasted, provided opportunity for learning and provided a sense of purpose. Those plwMND with greater levels of disability reported that they did very little outside their homes and had hoped the project would give them something to do and enable them to meet new people. The opportunity to engage in activities was important for all plwMND, and the need to find purpose and to be included was apparent when describing the challenges they had experienced since diagnosis.

"So it was a massive change to me a massive lifestyle change and I was very lost I think and I think more than the physical things to deal with, the psychological was harder for me.. and I felt like I needed support with that where to change my life some direction and support with sort of being included into new things really"

PlwMND 2

"well I've always been you know active, I've always walked and play golf and obviously both of those activities now have been taken away from me erm and erm I used to attend a lot of social functions at various golf clubs, I can't now."

PlwMND 5

3.2 | Aids and adaptations

Some plwMND had seen deterioration in their mobility since recruitment to the project. The need and subsequent wait for home adaptations had hindered their ability to leave their properties using their wheelchairs. The type of wheelchair was reported to hinder

access to transport whether that be difficulty dismantling and lifting or the need to use a wheelchair accessible taxi and associated costs. The link workers felt those plwMND who had been diagnosed longer or were experiencing more physical impairments particularly around mobility faced the greatest challenges to participation. Link workers reported the most significant barriers to participation were waiting for equipment provision or the completion of home adaptations. Some participants also highlighted that experiencing milder symptoms and retaining the ability to drive was a crucial factor in enabling people to participate in meaningful activities.

"I couldn't get out 'cause my legs have gone worse so there's only my dad and my friend who are able to push me in a manual wheelchair and I was issued a wheelchair but it was unsuitable 'cause it couldn't fold. I'm just waiting to get more practice."

PlwMND 4

"...a couple of the clients I seen they were like at different stage of getting like different equipment to support them like wheelchairs and mobility car and stuff like that you know so and on that basis they were reluctant to participate in activities."

Link Worker

3.3 | Confidence

The project helped some plwMND to participate in activities when they felt unable to do anything and gave them the confidence to engage in further activities. Prior to the project, some plwMND reported having experienced a lack of confidence in their ability to use their electric wheelchairs and did not feel they would be able to go out independently. Many plwMND were also reluctant to ask for help because of their previous independence, and the lack of someone to go with consistently to activities prevented participation. Having active support from family, friends or a volunteer was seen as a need for plwMND, which was mirrored by link workers who saw a lack of available support to accompany the plwMND to an activity as a barrier.

"...I've not been making use of that wheelchair the way I should do, I am nervous you know about it..."

PLWMND 5

"they've lost a lot of confidence and ok, from a practical viewpoint they're waiting for machinery from a confidence viewpoint it's when that machinery comes suddenly that's a whole different ball game of how do I use that, what happens if I go out and the battery runs dead on the wheelchair, or what

happens if I come across a ramp or that I can't get up or other issues when I'm out when I haven't anticipated..."

LINK WORKER

"...because it's occurred to me that a patient might think oh I'd like to do that but they're reliant on somebody else to take them there and that must feel horrible, really strange when you've been independent and all of a sudden you think oh I'd quite like to do that the loss of independence but that would mean somebody taking me so that's a challenge for anybody with a disability."

LINK WORKER

3.4 | Stigma

Difficulties fitting into some groups and being able to connect with the other group members was highlighted by some of the plwMND. This was in relation to differing diagnoses and perceived potential to negatively impact on the groups discussions or feeling obliged to continue participating despite fatigue due to being in a group setting, and experiencing stigma surrounding their diagnosis. Alternatively, the group itself was not perceived as positive in their outlook and therefore not a desirable group to be with. Lack of awareness of disabilities by the general public was felt to hinder access to the community with examples given such as people blocking drop down curbs and being less aware of wheelchair users.

The link workers felt some groups might exclude people based on their disability due to prejudice and concern about managing a person with a complex condition. The plwMND and the link workers highlighted the lack of activities in some geographical areas. The link workers reported a number of barriers related to local infrastructure. The inaccessibility of some community buildings, lack of suitable transport and cuts to funding were raised as barriers. All the link workers referred to the need to have community activities to refer to and felt adequately resourcing community groups should be a priority.

"I don't want to listen to other people's er problems in a way or er, I want to, I need to listen to positive, and I thought well that's fair enough it's just, just the way I felt at the time you know erm so I thought well I will give that a miss."

PlwMND 1

"...my partner works at like six in the morning and then when he comes home I can't really expect him to like take me over the water 'cause he wants to go to bed for an hour 'cause he's been up since like five...and my

dad's only just got on my car so at the time I couldn't really rely on my partner to like to take me."

PlwMND 3

"an organisation called XXX so if we speak to people anywhere in Liverpool and they say I've got a disability but I'd really like to join an art group and we think ah XXX will pick you up, but they're under threat of closing and we're thinking that's really going to be such a loss isn't it if it does go."

LINK WORKER

3.5 | Link workers' experiences

Reflecting on their own experiences of working with plwMND, many link workers felt it had been emotional due to the severity of the difficulties plwMND face. One way of managing these emotional experiences was via peer support and debrief with colleagues. One link worker spoke about being frustrated and wanting to work with an individual with MND earlier on in their diagnosis as they felt this would have increased the likelihood of sustained participation.

"I think emotionally it was quite challenging emotionally because on a few of the visits I actually came back and said to people I've found it really upsetting, no I did really because its, it's on a personal level you're meeting somebody who's had a really bad diagnosis well I found it 'cause the first, the first er woman we met she just really it's such a devastating diagnosis isn't it so I did find it, I couldn't stop thinking about it, as time goes on obviously but initially I think that's awful."

LINK WORKER

3.6 | Training needs

When reflecting on their experience of working in partnership with an occupational therapist, the link workers valued access to medical knowledge and expertise in the assessment of abilities of the plwMND and adaption of activities. They reported learning to adapt their communication approach to meet the needs of the plwMND had been valuable. All the link workers felt they needed further understanding of MND and would want to access training. They all felt working jointly with occupational therapy was beneficial to them and their clients.

"I don't feel that at the moment you could say to me actually XXXX here's ten clients you go for it off you go because I don't think I've got and I never will have

the medical level of knowledge and it needs that doesn't it, it needs both, it's got to be a partnership.."

LINK WORKER

4 | DISCUSSION

This appears to be one of the first studies to have evaluated the barriers and enablers to implementing a social prescribing service for plwMND, highlighting that plwMND who were newly diagnosed with mild symptomology were able to participate more easily in their chosen activities due to the lack of physical-related barriers.

Existing services are often little adapted to the fast-changing needs of plwMND (i.e. Van Teijlingen, Friend, & Kamal, 2001), with family carers equally reported to struggle receiving the right levels of support after a diagnosis of MND of their loved one (Aoun, Deas, Kristjanson, & Kissane, 2017; O'Brien, Whitehead, Jack, & Mitchell, 2012). Therefore, enabling plwMND in engaging in meaningful activities is a vital priority in providing suitable care. Mirroring these reports of inadequate service provision in MND, this study attempted to breakdown existing barriers, while also highlighting many difficulties that still remain in enabling participation. In particular, participation was seen to help adjustment to giving up work and provided purpose, with overall participation considered to improve well-being. This supports findings observed in other patient groups who have accessed social prescribing (The Kings Fund, 2017), while also supporting evidence from other neurological conditions showing that engaging in social activities is linked to improved levels of QoL (Giebel, Challis, & Montaldi, 2016). With other research highlighting that plwMND value receiving support to maintain psychological well-being (Schlüter et al., 2018), this study clearly addresses an important area in MND care which requires further attention on a larger scale.

PlwMND with moderate physical difficulties, particularly impaired mobility, found participation most challenging. Participants highlighted barriers relating to transport, equipment provision, lack of company to support participation and lack of confidence using mobility aids in a community environment. Link workers highlighted the same barriers. Due to the progressive nature of MND, it is often difficult for services to respond to the plwMND' rapidly changing needs (Giebel et al., 2019). One way to enable improved access to meaningful activities was suggested to be increased provision of easily accessible transport and befrienders. Indeed, befrienders are a common and effective way to not only enabling access to activities for more vulnerable groups but also to improve emotional well-being (Giebel et al., under review; Smith, Drennan, Mackenzie, & Greenwood, 2018). Future research needs to explore the quantitative effects on well-being of engaging in this social prescribing service, while these first qualitative findings already add important novel findings into an emerging area of clinical practice and research.

While limited research has explored the barriers and enablers to participation for plwMND, the challenges faced by the

participants included in this project echo those barriers highlighted by evidence on access to exercise and sport for people with physical disabilities (Jaarsma, Dijkstra, Geertzen, & Dekker, 2014; Sport England, 2016). The link workers identified the need for adequate funding of community groups as without them they would not have the activities for their clients to access. Previous studies that have considered the barriers and enablers to the implementation of social prescribing highlight the need for a whole system approach with a focus on local infrastructure, involvement from clinical commissioning groups, council services and the third sector would be essential (Pescheny, Pappas, & Randhawa, 2018; Skivington et al., 2018).

4.1 | Limitations

It is recognised that the project included only a small number of participants, however, considering the relatively small population of plwMND, and the fast progression of the illness within only a couple of years, this study is benefiting from a reasonable sample size for this population group. Furthermore, a limited number of link workers are employed in the region of the North West Coast of England, who were actively involved in this pilot service. Therefore, only four link workers could be interviewed. Future research needs to quantitatively evaluate this social prescribing intervention across a larger population group. Nevertheless, this pilot implementation study already identified qualitatively positive outcomes of this intervention, providing a strong case for a larger roll-out of the service to address QoL.

5 | CONCLUSIONS

This pilot implementation study provides the first evidence demonstrating that plwMND value participation and want to engage in community-based activities, thereby improving their QoL. Social prescribing was developed to meet the needs of people living with long-term conditions, however, given the barriers to participation described in this project, plwMND with more complex needs are unlikely to be able to access this intervention without facing a number of challenges. Social prescribing pathways should be established that bring the expertise of AHPs, in particular, occupational therapists and link workers together to prevent an increase in health inequalities for plwMND. This is corroborated by the social prescribing framework, which recommends a collaborative approach between AHPs and link workers (Royal Society of Public Health, 2019). In order to address wider barriers to participation, a whole-systems approach is required, including the consideration of local infrastructure. Further research is required to determine how best to implement a social prescribing model for plwMND and other neurological conditions, such as dementia, to prevent further health inequalities for this group.

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CONFLICTS OF INTEREST

None.

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