

Ghosh, Malabika, Bhagat, Priti and Cox, Diane ORCID: <https://orcid.org/0000-0003-2691-6423> (2022) How can a person-centred approach to occupational therapy practice in the community enhance independence for people living with complex neurological presentations? *British Journal of Community Nursing*, 27 (9). pp. 426-430.

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How can a person-centred approach to occupational therapy practice in the community enhance independence for people living with complex neurological presentations?

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Background

Neurological long-term conditions refer to a group of neurological disorders with varying life expectancies, which show gradual deterioration, ultimately leading to death (NHS England, 2019). Conditions such as multiple sclerosis, motor neurone disease (MND), Parkinson's disease and multisystem atrophy are examples of conditions that fall under this category (NHS England, 2019). These disorders are characterised by gradually deteriorating function, increasing care needs and varying levels of functional dependence. A multidisciplinary, palliative care team approach is recommended for managing the care needs of people who have terminal disease (Høgdal et al, 2020). According to an NHS England paper, neurological conditions consume about 14% of the social care budget, with most deaths likely to occur prematurely. People with neurological conditions have the lowest health-related quality of life compared to any long-term condition and experience severe mental and psychological burden (NHS England, 2019). Moreover, if the condition involves gradually deteriorating functional ability, planning ahead to maintain independence at different stages of the disease trajectory can be very difficult.

Occupational therapy intervention is recognised as one of the key components of managing functional decline in long-term neurological conditions (Høgdal et al, 2020). Tavemark et al (2019) recognise the significance of participation in activity to maintain independence, dignity and quality of life. However, there remains limited guidance on the specific nature of interventions involved that can help achieve this. Additionally, patients who are dying have individual needs, therefore making it difficult to generalise a list of interventions that may be used by occupational therapists. Furthermore, a study by Høgdal et al (2020) reports that patients with chronic advanced disease have high levels of unmet needs which they are unlikely to discuss with their doctors. This points to the need for including specialists like occupational therapists within the multidisciplinary team who can help manage these needs. Additionally, in a King's Fund paper, Coulter and Collins (2011) stress the importance of shared decision making and suggest that expert clinicians should work in partnership with their patients, involving them in their care decisions wherever possible. Not only is this ethically imperative, but there is rich evidence that patients who are actively involved in their healthcare have far better outcomes than those who are passive recipients of care.

This review paper discusses a community-based patient case study, describing a person-centred approach to occupational therapy practice that uses easy-to-initiate innovations aimed at meeting specific individual needs. The aim of the paper is to highlight the significance of person-centred care which has the potential to impact on the quality of life and the lived experience of the patient and their family, especially for people who have progressive neurological conditions.

Relevance

The use of meaningful occupation within various roles across the lifespan is a central concept of occupational therapy. Occupational therapy literature provides many definitions of the term 'occupation'. According to the Canadian Association of Occupational Therapists (1997, p.3): Occupation refers to groups of activities and tasks of everyday life, which are named, organised, given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity). Occupation is the domain of concern and the therapeutic medium of occupational therapy.

Of all the key features of occupation described above, the components particularly relevant for this case study discussion include the value and meaning attributed to occupation by individuals and the cultural perspective it underpins.

The case study

This case study is based on a patient diagnosed with MND and has been written using a reflective process to illustrate the occupational therapy intervention. MND is a progressive, neurological condition mainly involving motor weakness and cognitive decline. It affects muscles in upper and lower limbs, muscles of respiration and bulbar function affecting speech and swallowing (Ghosh et al, 2016; McDermott and Shaw, 2008). Currently there is no known cure for MND and supportive management of symptoms provided by the multidisciplinary team form an important aspect of management (Mcdermott and Shaw, 2008).

In this case study, the person will be referred to as BT and the review will focus on the therapeutic significance of occupation performed with choice and control by the patient. It will also highlight partnership working across services and teams required for optimal care in the community. Hammel (2017) talks about occupational engagement as a right and has highlighted that occupations that are individually or collectively valuable, enhance wellbeing and add meaning in life. The paper stresses on the need to have the opportunity to express choices and for professionals to empower individuals to enact those choices because this is critical to wellbeing.

History of presentation and home circumstances

BT was diagnosed with MND in January 2018. Following numerous multidisciplinary team interventions from the MND service, he was referred to the community rehabilitation occupational therapy team in February 2019. BT lived in a small, semi-detached house with his wife. His house was assessed for environmental modifications by social services, but since this is a means tested process, he had to fund potential modifications to his property. Due to the limited space indoors and externally, common environmental modifications such as through-floor lifts, ground floor bathroom extensions were not practically possible within BT's home.

Prior to his illness, BT led a very active life and enjoyed fishing and gardening as leisure activities. These leisure pursuits had to be discontinued as his physical abilities deteriorated, which had a big impact on his emotional wellbeing. His wife worked full-time. However, following diagnosis, she made the decision to stop working, to care full-time for her husband. This decision involved significant personal, emotional and financial sacrifice on her part. The level of BT's dependence during daily living activities directly impacted on the care that was provided by his wife. Over a period of time, this had the potential to cause significant carer burden. This is further highlighted by a study by O'Brien et al (2012) which found that failure to support family caregivers of MND increases the burden on them and if allowed to continue, may affect where the patient is cared for along the disease trajectory. It also has health and social care funding ramifications.

Progressive deterioration in condition and prescription of specialist equipment

By July 2019, BT had started to struggle to get out of his chair. A specialist chair assessment was completed by the occupational therapist. Although BT had a stairlift installed in the house, he was struggling to use it. Instead, he slept on a profiling bed downstairs. He was able to mobilise with a three-wheeled walker for short distances indoors and used a powered wheelchair when he went outdoors. A ramp was installed to the rear of the property to help with access. BT also needed the use of non-invasive ventilation (NIV), a technique used to support his breathing (Howard, 2020). At this point, BT was receiving 'continuing healthcare funding' (NHS England, 2021), which was used to pay for his care needs. Despite several assessments and trials, no suitable chair was found to meet BT's postural and transfer needs via statutory equipment services. A grant application was therefore made to the Motor Neurone Disease Association (MNDA, Unpublished data) to allow the team to look at sourcing a bespoke chair. Unlike statutory services, the MNDA grants are not means tested (MNDA Support Grants Guidance, 2022). They help to cover a percentage of the actual cost of equipment or adaptation. MNDA grants allow equipment or services to be accessed in a timely manner, which means patients like BT can be helped to maintain their quality of life and ability to function despite physical deterioration (MNDA Support Grants Guidance, 2022). This is extremely useful because bespoke equipment can be very expensive and can sometimes take quite long to procure via statutory routes. A few weeks after application, BT was approved for funding for a specialist chair via the MNDA grant.

By March 2020, BT needed a stand-aid to enable sit-to-stand transfers. This is a piece of equipment that requires a patient to hold onto the gripper bars while gently bringing them to a supported standing position. Although BT was struggling to transfer, once he was up on his feet, he was able to mobilise for a few steps within his room. This soon became an activity which BT was determined to preserve. BT and his wife were very keen to continue to participate in this meaningful occupation.

Due to deteriorating upper limb strength, within a few weeks, BT was unable to use the sit-to-stand hoist. BT's carers informed the MND occupational therapist that they could not support BT during sit-to-stand transfers providing manual assistance, as was being expected by BT and his wife. BT was not ready to consider a more supported method of transfer, which meant he would use a hoist. For him, that meant losing his independence. Hence, BT and his wife decided that she would help him with manual assistance during transfers so that he could continue to mobilise as long as possible. The occupational therapist worked very closely with the family and the care agency to prevent a

communication breakdown between the two parties leading to a crisis in care provision and to ensure BT was cared for safely even when moving and handling was carried out by his wife. Several sessions were devoted to training professional and family carers to improve awareness and management of BT's postural needs, including neck weakness and care needs.

Effect of the covid pandemic on care provision

The start of the COVID pandemic threw healthcare services in a state of chaos due to the need to follow infection prevention guidelines and use of personal protective equipment (PPE) and forced professionals to accommodate these needs in a very short span of time (Ghosh and Cox, 2021). By April 2020, physiotherapy colleagues from the local team had to step in when BT's care agency pulled out at short notice because care staff had not been fit-tested for face masks necessary to protect against aerosol generating procedures (Howard, 2020). Aerosols refer to small droplets of bodily secretions that may carry infection if a person has a transmissible disease, for example, COVID-19. Machines such as ventilators used for supporting respiratory function, produce aerosols (Howard, 2020). Therefore, during the pandemic it became mandatory to wear special masks to protect carers from potential aerosols. BT's use of non-invasive ventilation (NIV) was classed as aerosol generating (Howard, 2020). Hence, his care agency required the carers to use the highest level of precaution against covid infection, when caring for him. The community physiotherapists and respiratory specialist occupational therapist helped support BT's activities of daily living (ADL) needs. The therapy team enabled personal care and manual handling until BT's carers could resume. This is not usual practice for this community based service; however, given the impact of the pandemic on vulnerable patients like BT, the community therapy team upheld person-centred practice so that BT could stay at home. This was a great example of how professionals put patient needs at the centre of their practice, blurring professional boundaries to enable activity participation in meaningful occupations. Throughout the process, the occupational therapist based within the MND team worked closely with the community occupational therapist and care teams. Since the MND team is usually the first point of contact for the family and care team, the enhanced communication and joint use of expertise between professionals across teams ensured that BT's needs were met in a timely manner.

Further deterioration and need for bespoke specialist equipment

By July 2020, carers started to struggle to move and handle BT who required increased assistance transferring from his chair. There was limited room in the living room. Accommodating a hoist meant the potential need for rearranging furniture and other belongings in the room, which was unacceptable for BT and his wife. There was also a need for more frequent care visits, which they were keen to avoid. The local hospital's senior safety advisor who specialises in moving and handling was also consulted for advice on ways to meet BT's complex care needs. Following assessment, a 'sit-to-stand' lift cushion was recommended which would help to raise BT to a supported standing position (Tierney, 2015). Using this assistive equipment would mean BT could be more independent getting out of a chair, thus reducing the risk of injury to his carers from poor moving and handling techniques. The stair lift was also raised by 6 inches to facilitate transfers and to allow BT to use the upstairs bathroom.

By December 2020, BT's lower limb strength started to deteriorate, so stair lift transfers were no longer possible. This meant that an alternative toileting solution was needed downstairs. BT remained averse to using the hoist as he was able to take a few steps and was keen to preserve his independence. Several alternate commode options were sourced but none met BT's needs. The occupational therapist arranged a joint visit with an engineer volunteer from the charity, Rehabilitation Engineering Movement Advisory Panels (REMAP). The charity specialises in custom-designing equipment to help people with disabilities live more independent lives (REMAP, 2022). The aim was to assess BT's commode transfers and provide bespoke solutions. The engineer decided to explore making a new set of adjustable legs for the commode that could provide the extra height needed to ease transfers. The new commode was ready within a week. A seated stability and weight tolerance test (wobble test) was trialled by the occupational therapist and engineer at the workshop and the equipment was deemed stable. A measured risk approach was taken to trial this option versus the risk of poor moving and handling technique with the existing commode. Finally, BT was once again able to transfer off the commode with very little support from carers and his wife. It was the best outcome for BT, his wife and the care team.

BT passed away in February 2021. The multidisciplinary team involved in his care upheld his wishes and dignity till the end. BT's wife was extremely thankful to the team for their continued support of BT through their functional decline across their condition trajectory (Table 1).

Significance for occupational therapy practice

Client-centred practice is advocated as the core of occupational therapy practice (Hammel, 2013). Fisher (2013) used the term 'occupation centred practice' which places occupation at the heart of occupational therapy practice, research and education. The use of meaningful occupation in this paper emphasises the importance of being occupation based, person-centred and occupation-focussed where the emphasis is on occupation being the main intent of intervention, thus facilitating occupation-centred practice.

Box 1. Table illustrating the change in function and specialist equipment provision across BT's disease trajectory

	January 2018	October 2019	March 2020	April 2020	July 2020	December 2020	February 2021
Timeline of change in function		Diagnosed with MND. Difficulty with swallowing, slurring of saliva,	Assistance for mobility, transfers and most activities	Pandemic related effect seen on	Community therapy team input to support	Maximum manual assistance required	Struggling to manage toilet transfers even with manual assistance

	marked limb wasting	of daily living	care provision	care provision	for transfers	
ALSFERS Score	40	22	16	16		12
Timeline of specialist equipment provision	Home adaptations considered were found unsuitable for future-proofing property	Ramp, wheelchair, stairlift, three wheeled walker, non-invasive ventilation	Stand-aid, profiling bed		Lift cushion for transfers	REMAP input for bespoke modification to commode

NOTE: MND=motor neuron disease; ALSFRS= Amyotrophic Lateral Sclerosis Functional Rating Scale.

Source: ALSFRS (1996)

Today, there is an increasing acceptance of placing the patient's needs, wishes and preferences at the heart of any clinical decision-making process. A paper by the King's Fund 'no decision about me without me' remains a prime example of the emphasis on shared decision-making which advocates supporting patients so they can articulate their wishes and needs regarding the management of their condition (Coulter and Collins, 2011). However, this should be true not just for medical management alone. The entire process of multidisciplinary assessment, decision-making and intervention should hinge on this premise too.

In this case study, the patient's choice and dignity was maintained throughout the care process. The universality of dignity is seen in worldwide empirical research evidence which suggests that for a positive healthcare experience it is important for the patient to feel that their dignity is upheld and for the healthcare professional to see it as a valuable part of their professional practice (Harst de et al, 2018). For BT, the ability to transfer as long as possible without a hoist and being able to use the toilet independently was important for his dignity and quality of life. The willingness and ability of his professional team to explore specialist equipment beyond what is commonly provided through statutory services, was invaluable for BT. Harst de et al (2018) highlight that any condition where there is a loss of function and participation in life roles can alter the existential self-image of a person. In addition, the worry about impending death can be a huge emotional burden on the person involved and the family, often leading to a loss of dignity. Given the rapid progression in BT's

condition, maintaining dignity for BT and his wife throughout the caring process was a significant goal for the whole team. Using innovative solutions such as REMAP to provide bespoke solutions in a timely manner, helped promote patient choice and independence till the end of life. Additionally, by supporting BT, the team empowered his wife, who was his main carer and who had put her own life on hold to care for her husband. As has been stressed by Hammel (2017), the opportunity to express choice and the willingness of professionals to look into these choices is important for wellbeing. In this case study, it was empowering for BT and his wife and helped enhance wellbeing throughout their care process.

Close collaborative working between the occupational therapists on the MND team and in the community, along with BT and his wife and care teams, helped achieve patient-centred and occupation-centred care within a collaborative, shared decision-making model, upholding the values of dignity in care. This is how all multidisciplinary team working should be, most importantly in palliative care for clients with a diagnosis of a terminal illness.

Implications for care teams based in the community

The National Institute for Health and Care Excellence (NICE) guidelines for MND advise that regular assessment by the multidisciplinary team be carried out to ensure the provision of equipment and adaptations in a responsive manner in keeping with a person's changing needs (NICE, 2016). Timely assessment, specialist equipment and adaptations provision directly helps to impact on the person's quality of life. Not only does it allow people to continue activity participation and meaningful occupation (Hammell, 2013), but it also helps to reduce the likelihood of harm from adverse events such as falls (NICE, 2016). Although the NICE guidelines recommend ongoing assessment every 2-3 months, our experience of dealing with patients with neurological conditions such as MND, is that intervention towards the end of life can be very intense and urgent, sometimes changing every few days. The occupational therapist is an integral part of MND management across the disease trajectory, from diagnosis until the end of life (Ghosh and Cox, 2021).

The World Federation of Occupational Therapists' (WFOT) position on end-of-life care further highlights the contribution that occupational therapists can make in end-of-life care through the promotion of personal growth and development (WFOT, 2016). It recognises that participation in occupation can be transformational, especially for those approaching the end of life (WFOT, 2016). As such, the WFOT recognises that occupational therapists have the ability to make a substantial impact to end-of-life care teams and bring value to the understanding of how people wish to continue life in the face of declining function and terminal illness (WFOT, 2016). Our experience has been no different. However, it is important that clinical practice is patient-centred, occupation-focussed and based on shared decision-making. The current landscape for the presence of occupational therapy on end-of-life care teams is optimistic, although it may need ongoing advocacy, funding and support to meet individual needs.