Interdisciplinary Collaboration in the use of a Music-with-Movement Intervention to Promote the Wellbeing of People with Dementia and Their Families: Development of an Evidence-based Intervention Protocol

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Abstract

The music-with-movement (MWM) intervention is particularly suitable for people with dementia (PWD) because their gross motor ability is preserved until at the later stage of dementia. This study aims to examine the effect of MWM on reducing anxiety, sleep disturbances, and improving the wellbeing of PWD. This paper reports the first stage of the study - developing the intervention protocol that staff can use to teach family caregivers. A registered music therapist (MT) developed and taught staff of two social service centers the MWM protocol over five weekly 1.5 hour sessions, with center-in-charges (social workers and occupational therapists) and the Team (nursing; hereafter called the Team) joining these sessions to provide comments from their professional perspective. Each discipline had different expectations about the content of the protocol. Numerous meetings and discussions were held to bridge these differences and fine-tune the protocol. Few healthcare professionals doubt the merits of interdisciplinary collaboration at all levels of health promotion. In practice, interdisciplinary collaboration is complex and requires commitment. Openness and persistence is required from all stakeholders to achieve a successful intervention for consumers.

Keywords

Anxiety, Dementia, Interdisciplinary collaboration, Music intervention, Sleep disturbance, Protocol development

Introduction

Recent research has found that over 40% of people with early dementia (PWeD) display significant subclinical or clinical anxiety (Hynninen *et al*., 2012). Thirty percent of PWeD also suffer from insomnia (Rongve *et al*., 2010). These problems also induce distress in family members, affecting their wellbeing and quality of life (QOL). The ability of music to effect changes in mood and emotion has touched the lives of many people. Music therapy is used to enhance cognition (Svansdotti & Snaedal, 2006), reduce depression (Maratos *et al*., 2008), promote sleep quality (Lai & Good, 2005), manage anxiety and psychological problems (Svansdotti & Snaedal, 2006), and so on.

The aim of our study is to investigate the effects of using music with movement as an intervention to promote the wellbeing and quality of life of PWeD by reducing anxiety and sleep disturbances. This paper reports stage one of the study, which is the development of the MWM intervention using a "train the trainer model."

Literature Review

Anxiety and Sleep Disturbances experienced by PWeD

PWeD often display psychological symptoms and behavioral problems related to depression and anxiety (Andreescu *et al*., 2014). According to Mintzer *et al.* (2001), the most common disorder experienced by PWD is generalized anxiety disorder. Unlike depression, anxiety in dementia has received less attention (Hynninen *et al*., 2012). Neurological changes and the challenge of effectively expressing oneself because of a deterioration in one's verbal communication skills could be among the causes of anxiety felt by PWeD (Bossen *et al*., 2009). Furthermore, the diagnosis of a non-curable progressive disorder and fear of the future likely also contribute to the presence of anxiety (Riley *et al*., 2014).

Treating anxiety in dementia is essential, as such anxiety often leads to behaviors that could have a negative effect on others and on the PWeD. It may also lead to an increase in unnecessary medication, a lower quality of life, institutionalization, greater caregiver distress, and mortality (Riley *et al*., 2014).

Around 30-45% of PWD also suffer from insomnia (Rongve *et al*., 2010). Although sleep problems are common among elderly people, sleep disturbances including insomnia and other nighttime behaviors have been found to be more common in PWeD than in cognitively normal elderly people (Blackwell et al., 2006). Sleep disturbances in PWD mainly relate to disturbances in the sleep-wake cycle, i.e., sleeping during the day and being awake at night (McCurry *et al*., 2000). They are thought to be a very early marker of dementia, and it has been suggested that promoting sleep could have an effect on cognitive decline (Elwood *et al*., 2011). Specifically, promoting sleep is thought to be beneficial in managing sundowning – excessive night-time activity that has been identified as one of the main reasons for moving PWD to institutionalized care – and even the progress of dementia (McCurry *et al*., 2007).

The Uses and Effects of Music Intervention

Research has shown that stress and anxiety can be reduced by using music therapy (Sung et al., 2006; Svansdottir & Snaedal, 2003), and that music promotes relaxation by reducing levels of circulating noradrenaline (Gerra *et al*., 1998) and other stress hormones (Suzuki *et al*., 2004).

Listening to music has been the most frequently used technique to promote sleep (Chang *et al*., 2012). Chang *et al*. (2012) showed that music therapy, when used among adults experiencing insomnia, can prolong REM sleep and significantly improve rested rating scores. Chan (2011) found that music led to improvements in the sleep scores of elderly people. Reglio *et al*. (2008) studied the effects of using music therapy to mitigate the behavioral problems of

PWD and observed a significant reduction in nighttime sleep disturbances. Music therapy is therefore a promising non-pharmacological intervention to manage anxiety (Ueda, 2013) and improve sleep (Lai & Good, 2005).

MWM intervention is suitable for PWeD

Among various types of music intervention, the MWM intervention had been recommended for PWD (Gfeller & Hanson, 1995). It has previously been used as an intervention for PWD in Taiwan (Sung *et al*., 2006), Hong Kong (Cheung *et al*., 2012), and Belgium (van de Winckel *et al*. 2004). MWM is an approach that involves the movement of gross bodily muscles with preferred music; no fine muscle coordination or verbal ability is required during the intervention. PWD experience a general cognitive decline that affects their verbal skills at a relatively early stage, reducing their receptive and expressive communication skills. Their gross motor ability, however, is better preserved until the later stage of dementia is reached (Bossen *et al*. 2009). This is the advantage of using MWM as a therapy for PWD. Although the focus of MWM intervention is not on bodily exercise, it still engages the PWD in activities that to a certain extent, exercise the body. Robust evidence about the benefits of exercise have been reported in the literature, for instance, physical outcomes such as balance and mobility (Liu & Latham, 2009), psychosocial wellbeing (Yan et al., 2012), and social interactions (Lord et al. 2003).

Moreover, not all participants like music interventions that require them to sing along. Broton and Pickett-Cooper (1996) pointed out that 20% of participants in their study disliked singing, but did not express any dislike for the MWM modality. This is consistent with the finding of a recent study that 23% of the elderly participants expressed a dislike of singing when it was required as part of the music therapy (Sakano *et al*., 2014). Gfeller and Hanson (1995) also concluded that participants who took part in movement activities were better able to interact with others than those who had only joined the singing group. MWM is therefore a promising modality for promoting the wellbeing of PWD.

Both anxiety and sleep disturbances have been found to impair the quality of life (QOL) of PWeD (Riley *et al*., 2014; Rongve *et al*.2010). Our study is an investigation of the effects of using music with movement as an intervention to reduce anxiety and sleep disturbances in PWeD, and consequently to promote their QOL.

The intervention for PWeD in the community is to be delivered by family caregivers. This paper reports only stage one of this study. This involved asking a registered music therapist (MT) to train staff of two participating senior centers to use the MWM intervention protocol designed by the research group.

Study Aim

The aim of this paper is to report the processes followed by our Team (the research team), and their experiences, when developing the MWM protocol that was finally accepted by all stakeholders concerned. The stakeholders in our study include the members of the Team, the music therapist, social workers, nurses, and occupational therapists. Also shared are the lessons learned about interdisciplinary collaboration in research, specifically about the work involved in developing intervention protocols.

Methods

Design

Our main study adopts a mixed methods design with the quantitative paradigm being the main research approach. We aim to investigate whether an MWM intervention would reduce anxiety and sleep problems in PWeD in the community. Recruited PWeD must be aged 65 or above, have a Clinical Dementia Rating (CDR) of 0.5 to 1, and have a primary caregiver who is willing to participate in the study. The quantitative arm of the study will be a randomized controlled trial. A naturalistic approach will be adopted for the qualitative arm (Lincoln, 1985), consisting of interviews with the participants (staff of non-governmental organizations [NGOs] and family caregivers) to determine the uses and effects of the MWM intervention from their perspective.

The first stage of the study involved designing an MWM protocol that reduces anxiety and sleep disturbances in PWeD. The Team then tested the protocol in two different community centers prior to letting the participating staff teach recruited families. To appraise the areas needing improvement in the initial version of the MWM protocol, we had observers in all of the sessions who were either the center-in-charge of the two study venues or the Project Coordinator (representing the funding body), and also members of our Team. The observations and comments from the NGO staff were then discussed in weekly meetings of the Team, the Project Coordinator, and the music therapist, so that adjustments to the protocol could be made.

Setting and Participants

The staff who joined our training program on the use of the MWM intervention were recruited from two not-for-profit NGOs run by charitable foundations that operate community services for PWD in Hong Kong. During this first stage, an opportunity sampling technique was used for recruitment. Posters advertising the "MWM Intervention Training for Staff" were put up in various social centers of the two NGOs. A total of 17 staff members were recruited in the two study venues – nine in one and eight in the other. The participating staff had to join a weekly training program of 1.5 hours each for five consecutive weeks. Each of them had to complete no less than 80% of the training program, and also had to give return demonstrations to the satisfaction of the MT or the trained research assistants in order to be permitted to deliver the MWM protocol. Staff participation was entirely voluntary and no payment was made to the NGO or any staff member. Ethical approval for the study was obtained from the Human Subject Ethics Sub-committee of The Hong Kong Polytechnic University (synonymous with Institutional Review Boards in other countries).

Results

Stage I: Developing the Initial Protocol

The development of the MWM protocol for PWeD in the community was based upon earlier work conducted by Daphne Cheung (nursing in background) in our Team, who developed an evidence-based MWM intervention protocol for nursing home residents with dementia. As PWeD are cognitively more capable than people with moderate dementia, Cheung's (2012) MWM protocol was modified to be more challenging for PWeD, to prevent them from becoming bored. For example, more complex movements, such as rolling the hands and making swimming arm movements, were adopted in motor imitation activities in the current study. In Cheung's (2012) study the participants were facilitated in playing handheld percussive instruments, while in the current study PWeD will be encouraged to sing along to a song while simultaneously playing the instrument. This will involve an integration of the auditory, speech, and motor functions, which might better suit the abilities of PWeD. Singing also helps to divert a PWD's attention to more positive events (Clair, 1996). Additional activities that require more cognitive processing but remain suitable for PWeD, such as rhythmic imitation with movements and Tai Chi exercises with music, were incorporated into the MWM protocol employed in the current study.

The MT, however, took to a different approach to preparing the MWM draft protocol. The MT designed the protocol based on theoretical principles of music therapy, experience working with PWD, and ideas and principles put forward by the Team based on their expertise in caring for PWD.

To make use of the emotional benefits of familiar music, the MT chose a variety of Chinese songs from the 1940s to 1980s to cater to the different music preferences of the participants. Sacks (2010) found that many PWD respond to familiar music. He suggested that familiar music triggers lost memories and emotions from the past, leading to a temporary state of mental lucidity and happiness. Familiar music provides structure, predictability, and a sense of security for PWD and helps to reduce agitation (Clair & Bernstein, 1995), and therefore possibly their anxiety level.

One of the purposes of employing music therapy for PWD is to maximize their ability and willingness to participate. Moving with the music to improve gross motor coordination will also enable PWeD to have a sense of success and competency (Ahn & Ashida, 2012). Successful experiences will in turn contribute to a higher level of emotional wellbeing. In the current study, the MWM will be implemented by caregivers, who may not be trained to interact with PWD. Based on the experience of the MT, instructions for caregivers have been included in the protocol to remind them to use positive communication skills, such as frequently offering positive reinforcement. The MT's experience is that a failure-free activity will more likely lead to enjoyment and improve the mood of PWD.

The research team (Team) specified the "dose" of the intervention for the MT to consider. The frequency of MWM intervention was set at 30 minutes per session and no less than three times per week for 12 weeks. Thirty minutes per session is the minimum time for optimal effectiveness in music therapy studies (Gerdner & Schoenfelder, 2010), because PWD cannot stay focused for very long). Craig (2014) suggested that the optimum frequency is two to three times a week for 30-50 minutes at a time. We also adopted Ceccato *et al*.'s (2012) 12-week duration in designing our protocol.

Before the initial version of the intervention protocol was finalized, it was circulated once more among the Team for comments. At this stage, the Team remarked mainly on the writing (stressing the use of plain and non-technical language) and the degree to which the activities were illustrated (urging the use of more examples or pictures to illustrate techniques). The Team also recommended the inclusion of more variations to each activity to meet the diverse needs of PWeD.

Stage II: Testing the Protocol

To test the protocol, we recruited staff from two elderly social service centers to participate in the MWM training. Over five weekly 1.5 hour sessions, the MT taught the staff of the social service centers the MWM protocol. During each session, the MT went through each of the activities, introducing the purpose and rationale for each activity, and particular points to note when teaching family caregivers.

When the first version of the MWM protocol was used in training, both the observers and the participants stated that it seemed to be too structured. Within the protocol, weekly instructions for five activity routines are presented in a fixed order for participants to complete. Each activity has particular songs prepared by the MT, from which the participants can choose. Before further refining the protocol, the Team decided to continue with two more sessions to allow more time for the participants to become accustomed to the protocol. After these two sessions, the participants (staff from the centers) expressed worries that such a structured program might be good for group sessions, but not for a one-to-one intervention to be conducted in a client's home. They commented that some activities such as "passing the balloon" might not be as fun and exciting in a dyad (consisting of the client and the family caregiver) as in a group. Some staff members believed that the program should be made more adaptable to PWD of varying capabilities and educational and functional levels. They also wondered what to do if a session turned out to be not to the participant's taste. For instance, moving to music with a stick to which a ribbon has been tied might be too feminine an activity for a male participant.

After a few sessions and a number of meetings, it became clear that the various stakeholders had their own expectations not so much about the content of the protocol, but about its delivery. A staff member with a social work background said, "To be honest, what benefit each activity brings isn't really important to me and my clients; what concerns me most is that if it is not fun, my client won't want to play at all." The social workers were also concerned about the practicality of some activities, for example, "What if my client had a stroke and cannot move the left side of his body?" Meanwhile, NGO staff with an occupational therapy background were mainly concerned about the physical benefits of the activities. Both the Project Coordinator of the funding body, who has a background in social work, and a member of the Team, raised further concerns about the practicality of the designed protocol. Their observation was that there was little room for the PWeD and family caregivers to choose their own songs or movements.

The rolling out of the protocol met with some issues that the Team had not anticipated. After the feedback, the MT worked to improve the adaptability of the protocol. More examples were included in each activity to instruct the participants what to do in certain scenarios, such as when the PWeD is unable or reluctant to perform certain activities.

Stage III: Refining the Protocol

In summary, the main criticisms of the original protocol were that it was: (i) too structured, (ii) lacked choices of songs, and (iii) did not cater to the needs of individuals. Many meetings and discussions were held to address these issues and fine-tune the intervention protocol.

The Team realized that such a highly structured approach to designing the protocol had come about because the MT interpreted intervention fidelity as ensuring sameness in the delivery of the intervention for the purpose of research. Clarifications were made to the MT about adhering to basic principles when using MWM. To ensure the development of an acceptable protocol and to avoid miscommunication, more phone, Skype, and face-to-face meetings were held. A member of the Team (a nurse) offered onsite feedback to the MT on how to motivate the staff to enjoy the intervention, so that the staff would be able to motivate the families to implement the intervention.

Eventually, some major changes were made to the design of the protocol and the ways of delivering it. First, we rewrote many parts of our instructional manual to make the protocol more flexible and easier to use. We added a table listing different kinds of activities and guidelines for ease of reference. The manual now makes mention of the equipment required and provides an explanation of the expected benefits of the activities. Also added were a second table and guidelines detailing alternatives for particular activities with comparable physical or cognitive benefits (e.g., activities to engage the large muscle group, a repertoire for enhancing the recalling of information such as the name of the song, etc.). More detailed descriptions are now given of how each activity can be conducted to cater to the needs of caregivers of varying skill levels in caregiving, and of the some potential specific needs of PWeD. Last, guidelines on helping participants choose replacement songs have also been included.

Second, with regard to the teaching, put more emphasis is now placed on how to assist PWeD to enjoy the activities, how to ensure that individuals with physical disabilities can perform certain activities, and how to choose music that fits particular movement regimens. Role plays were added as part of the regular teaching sessions.

Third, cue cards have been developed for the use of the participants. The cue cards, small enough to be held in a hand, are a compressed version of the instruction manual. They allow the caregiver to easily access information instead of having to flip through a thick manual. The cards contain pictures to help caregivers quickly identify what they are looking for.

Finally, the three main issues with the intervention protocol that were identified were addressed and the protocol was revised to the satisfaction of the Team, the MT, and the staff. A version acceptable to various stakeholders is now ready.

Discussion

One of the challenges that we encountered was that people from different disciplines had different expectations of what they wanted to achieve through the MWM intervention. This could have easily caused disagreements and even conflicts within the Team. Fortunately, all of the stakeholders were willing to voice their opinions and find common ground.

Several factors probably contributed to the differences in focus on the MWM protocol. To begin with, our professional training is different. Naturally, we perceive matters from our own disciplinary orientation. Also, the acculturation process in each discipline could have led to unconscious displays of territorial behavior (Axelsson & Axelsson, 2009). Last, not being members of the research team, the NGO staff were less inclined to pay special attention to the procedures crucial to maintaining intervention fidelity. To develop an MWM protocol that meets the expectations of those from different healthcare disciplines, frequent and open communication is required. The Team believed that all of the healthcare professionals who participated in the training sessions were client-centered, which was why we were eventually able to reach a consensus on the contents and delivery mode of the MWM protocol.

Interdisciplinary work was vital in the development of our MWM protocol for PWeD that can be implemented in people's homes. Interdisciplinary work means an integrated team approach to healthcare, involving the design, implementation, and evaluation of a treatment plan and options involving all members of the team, in consultation with patients and their families (Behm & Gray, 2011). Mickan (2005) found that interdisciplinary collaborations increase professional satisfaction, role clarity, and positive communication with staff and patients, as well as mutual respect between professionals in the team. Mickan also suggested that an interdisciplinary approach will lead to better health outcomes for patients and improve their satisfaction In our case, having people from different disciplines work together allowed the staff to understand how their work would contribute to the final product – the MWM protocol.

To design a successful intervention protocol for use in the community, we should always consider the dimensions of adaptability and flexibility in context (National Health & Medical Research Council, Australian Government [NHMRC], 1999). Getting the "buy-in" of frontline staff is essential. The promotion of evidence-based practice in healthcare is a continuous endeavor, not a one-off one

Clinical practice guidelines use standard clinical practices to help improve patient care. Although developing an intervention protocol is not exactly the same as developing clinical practice guidelines, the principles are fairly similar. Graham and Harrison (2005) argued that practice guidelines may have the potential to impact patient outcomes, yet the beneficial effects are contingent upon the successful implementation of the guidelines or protocols. These processes should involve a multidisciplinary group (NHMRC, 1999) as well as consumers. The more involved consumers – the service users – are, the more the researchers will learn what consumers need and how best to work with them (Oliver et al. 2004). In our study, the NGO staff, and the PWeD and their families, were all consumers of services.

A couple of systematic reviews of handbooks identifying key elements for developing evidence-based clinical practice guidelines are found in the literature (e.g., Ansari & Rashidian, 2012). Some of the key steps that have been identified are forming a guidelines development group, involving the consumers, and making group decisions. Regrettably, adequate details for the evidence-based development of guidelines are still rather limited in the literature (Ansari & Rashidian, 2012). Our experience is therefore useful for clinicians and researchers seeking to take a similar path.

Limitations

The experiences of this team in developing the MWN might not be entirely applicable to other teams, given differences in healthcare systems, culture of community centers, and the profile of the clientele of NGOs. Moreover, although cue cards with pictures are available to help family caregivers who are illiterate to carry out the MWM protocol, they might not be sufficient to develop the proficiency of these caregivers. Thus, alternative strategies on how to present the protocol should be considered, such as a video or audio version of the protocol. Our Team is considering moving in this direction.

Conclusion

Developing an MWM protocol involves first identifying different essential principles: the level of flexibility within each activity, the adaptability to enable the intervention to be carried out in different environments, and the ability to induce meaningful interaction between the caregiver and the PWeD. Interdisciplinary work can reveal specific points of view that only people from a particular discipline may be aware of. It is therefore vital in our efforts to develop client-centered services. It is often difficult to develop a protocol that can be recognized by people from different health disciplines; to achieve all of the expectations of people from different disciplines is even more challenging. Therefore, those from different professional disciplines need to clarify their expectations and identify modifications of the protocol that all can agree upon. Doing so would require better communication and less territoriality. It also takes time. However, with patience and open-mindedness, the development of such a protocol can be achieved.

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