

GUEST EDITORIAL

Non-pharmacological interventions for persons with dementia: what are they and how should they be studied?

The publication of four papers concerning non-pharmacological interventions for persons with dementia heralds progress in the science of dementia care. The four papers are very diverse in focus and methodology, and include a study of the impact of a visual arts program on quality of life, communication, and well-being by Windle *et al.* (2017); an overview of systematic reviews of pharmacological and non-pharmacological interventions for the treatment of behavioral and psychological symptoms of dementia by Dyer *et al.* (2017); a systematic review of the efficacy of intervention in people with Lewy body dementia by Morrin *et al.* (2017); and a protocol of the Behavior and Evolution of Young Onset Dementia part two (BEYOND-II) study, an intervention study aimed at improvement in the management of neuropsychiatric symptoms in institutionalized people with young onset dementia by van Duinen-van den IJssel *et al.* (2017).

The publication of this combination of wide-ranging papers on non-pharmacological interventions for persons with dementia raises the opportunity to discuss basic questions concerning such research. These questions pertain to the definition and understanding of non-pharmacological interventions, understanding the role of non-pharmacological interventions within subgroups of different types of dementia, and appropriate methodologies for examining the impact of non-pharmacological intervention on persons with dementia.

What is a non-pharmacological intervention?

In my opinion, non-pharmacological interventions for persons with dementia are those that directly address the unmet needs of this population, unmet needs which result from dementia related symptoms, including memory difficulties, limitations in activities of daily living, or inadequate communication abilities. Unmet needs have been found to provide the most convincing source for behavior problems, and responding to these needs results in a decrease of such behaviors (Cohen-Mansfield, 2013). Given that the most common

needs pertain to loneliness, boredom, pain, and discomfort (Cohen-Mansfield *et al.*, 2015), non-pharmacological interventions span a very wide range of actual interventions, of which the papers here mention visual arts (Windle *et al.*, 2017), music (Dyer *et al.*, 2017), exercise programs (Dyer *et al.*, 2017; Morrin *et al.*, 2017), or aromatherapy (Dyer *et al.*, 2017).

But, what about analgesic medication to address pain (Dyer *et al.*, 2017)? Should this intervention be considered non-pharmacological – based on the definition above – or should it be considered pharmacological – as it is in common usage? Furthermore, Morrin *et al.* (2017) includes deep brain stimulation, electroconvulsive therapy, and repetitive transcranial magnetic stimulation as non-pharmacological interventions. Although these interventions are not pharmacologic, they do not fit the above-suggested definition. Many have lamented the term “nonpharmacological” as it defines a phenomenon by what it is not, and the confusion illustrated above only highlights the need for a clearer definition and better terminology. Would the designation, “need-addressing interventions” be helpful? The term “psychosocial interventions” has been used by some, but it does not seem to capture the full range of treatments. Often addressing the specific need is most useful, such as “engagement” (interventions that address boredom) or “social” interventions (addressing loneliness), but a more global term is needed as well.

It is often difficult to gauge the nature of non-pharmacological interventions from the literature. For example, what is included in “music therapy” (Dyer *et al.*, 2017)? Does it include listening to music via headphones? Is the music individualized to the person’s past or current preferences? Is it a group activity of music appreciation? Does it involve singing, using musical instruments, or even dancing? Does the music therapist interact with each participant? It is likely that these different protocols may have a differing impact for different individuals. The paper on visual arts (Windle *et al.*, 2017) provides a very helpful, detailed description of the intervention available on the internet, while the study protocol for persons with young onset

dementia (van Duinen-van den IJssel *et al.*, 2017) provides only a general outline of the intervention, and will hopefully present a more detailed protocol of the intervention after the study.

In addition to understanding the nature of the intervention, it is important to recognize the elements that make it effective, its “active ingredients.” Regrettably, this is often absent from discussions of most non-pharmacological interventions. For example, in the various manifestations of “music therapy,” social contact could be an important ingredient, or this may be absent, and sensory stimulation might serve as the active ingredient, or perhaps it is an active connection to past emotions and identity that is the crucial element. Understanding the ingredients will dictate both choice of treatment in specific situations and methods for enhancing the intervention. The paper on visual arts (Windle *et al.*, 2017) does refer to active ingredients, discussing mentally stimulating activities, promotion of error-free positive experiences with opportunities for success, activities without stigma, and the fostering of creative aging. Social participation was included as part of the intervention, and “social inclusion” was a component in that artists were brought into the segregated living area of persons with dementia. Reflection on the active ingredients of intervention is likely to further the development of alternative interventions, to improve current interventions, and to promote the tailoring of interventions to specific needs.

Research concerning subgroups of persons with dementia

Two of the papers focused on subtypes of dementia, namely Lewy body dementia (Morrin *et al.*, 2017) and young onset dementia (van Duinen-van den IJssel *et al.*, 2017). Lewy body dementia is estimated to comprise between 4.2% and 7.5% of all dementia cases, increasing to between 7% and 11% when including Parkinson’s disease dementia. Young onset dementia is estimated to comprise between 6% and 9% of all dementia cases. Thus, it is not surprising that most studies of non-pharmacological interventions for persons with Lewy body dementia are case reports. In fact, this raises a number of underlying questions: Do behavioral problems manifested by persons with specific subtypes of dementia differ from those of other subtypes in their expression or in the circumstances of their appearance? Do persons with Lewy body dementia or with young onset dementia have needs which differ from those of people with other types of dementia? Is there reason

to think that non-pharmacological interventions addressing the needs of people with other types of dementia would not be appropriate for people with these subtypes of dementia? Should the principles of intervention be different? And practically, is it realistic to conduct intervention studies for low-frequency subpopulations?

Obviously, we are aware of differences in the manifestations of different subtypes of dementia, in that, for example, persons with Lewy body dementia exhibit greater fluctuations in function as well as an increased incidence of hallucinations. Yet, since most non-pharmacological interventions are person-centered and tailored to the needs and abilities of the individual, it seems reasonable to incorporate customary non-pharmacological interventions into the care of those manifesting less common types of dementia. If, however, focus on one of the less frequent subtypes is considered to be warranted, this will require large and well-funded studies. Alternatively, with technology, it may be possible to design studies which utilize a network of providers, each of whom could apply the study protocol within his/her professional environment.

Appropriate methodologies

The multiple methodological issues faced by studies of non-pharmacological interventions have been discussed elsewhere (Cohen-Mansfield *et al.*, 2014). The study of a visual arts program (Windle *et al.*, 2017) is a good example of a convincing mixed methods, multiple measures, multisite study. It is important that real-life clinical interventions be included in our literature and reviews, as their inclusion is more likely to lead to large implementation programs. The inclusion of all types of designs is also a strength of Morrin *et al.* (2017)’s review. In contrast, reviews that include only RCTs limit the understanding of the available information concerning non-pharmacological interventions.

There is a great need for research on non-pharmacological interventions for persons with dementia. We need to expand the toolkit of interventions, to clarify how to optimize the match between person, behavioral symptom, need, and intervention, and to find ways to promote actual implementation of research findings into different residential settings. In order to move this agenda forward, researchers need to demonstrate more flexibility as well as more rigor. Multiple types of research designs may maximize clinical opportunities. Thus, researchers need to optimize research designs to specific settings, interventions, and budgets. At present, non-pharmacological

interventions are like “orphan drugs” in that there are no organizations with a commercial incentive to invest large sums in testing them. Therefore, we need to use all opportunities to examine new approaches. Furthermore, the researcher needs to exercise much thoughtfulness in planning the study. Often the label of an assessment does not convey its full content or limitations; different assessments may be more or less appropriate for different stages of dementia; and different methods of administering an intervention may maximize its benefit for persons at different stages of dementia or from different cultural backgrounds.

The basic study of non-pharmacological interventions for persons with dementia is still in its early stages. We therefore look to our authors and the readership to pursue studies that will use this opportunity to enhance the quality of life of persons with dementia and their caregivers.

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