Dementia and Alzheimer's Research

TRO Research Hub: TR-Related Literature

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The closing group: Therapeutic recreation for nursing home residents with dementia and accompanying agitation and/or anxiety

Putman, L., & Wang, J. (2007). The closing group: Therapeutic recreation for nursing home residents with dementia and accompanying agitation and/or anxiety. *American Journal of Alzheimers Disease & Other Dementias*, 22(3), 167-175. doi:10.1177/1533317507300514

Long-term care residents who have a dementia diagnosis could account for as much 50% of a nursing home's population. Often residents with dementia experience a distressing behavioral symptom that affects the resident experiencing the symptom(s), other nursing home residents, visitors, and staff. The Closing Group intervention was developed as a nonpharmacological alternative that aims to reduce agitation and anxiety, increase socialization, decrease restraint use, and decrease antipsychotic drug use for selected residents with a dementia diagnosis. The program was based on an understanding of the contributing factors to agitation and anxiety, the nursing home environment as it relates to behavior, and the offering of resident-driven recreational activities. The purpose of this 2-year study was, with use of multiple measures, to examine the extent to which the Closing Group intervention has met its goals. A sample of 16 long-term care residents was offered attendance at the group. Findings in the area of reducing agitation and anxiety were encouraging to the extent that further study with larger samples is needed.

Keywords: nursing home residents, dementia, recreation, agitation, anxiety

Outdoor environments for people with dementia: An exploratory study using virtual reality

Blackman, T., Van Schaik, P., & Martyr, A. (2007). Outdoor environments for people with dementia: An exploratory study using virtual reality. *Ageing and Society*, 27(6), 811-825. doi:10.1017/S0144686X07006253

Few studies have investigated how outdoor environments might disable people with dementia. The issue is rarely considered in planning and design guidelines and not at all in regulations, despite dementia being within the scope of disability discrimination legislation in the United Kingdom and other countries. This article reports a study that involved older people with mild to moderate dementias taking two walks, one in a real town centre and one in a virtual reality (VR) simulation. Adaptations were made to the VR simulation to test possible design improvements. Overall, the town centre posed relatively few problems for the 38 older people with dementia who participated, although more difficulty was evident with greater impairment. Some features of particular places were liked more than others, particularly the segregation of spaces from motor traffic. There were measurable benefits from using clear textual signs to support wayfinding and to identify objects and places in the environment. Diminished outdoor activity is likely to be experienced as a decrease in quality of life and may accelerate the progression of dementia. We conclude that older people with mild to moderate dementia should be encouraged to be active outdoors and that this can be facilitated by small environmental modifications. Some limitations of the VR technology used for the study are also reported.

Keywords: dementia, environment, virtual reality, walking

Leisure as resistance within the context of dementia

Genoe, M. R. (2010). Leisure as resistance within the context of dementia. *Leisure Studies*, 29(3), 303-320. doi:10.1080/02614361003720570

Older adults are at risk of experiencing ageism, which can have negative implications for their quality of life. When diagnosed with dementia, older adults may experience increased stigma due to memory loss. However, leisure can be a space for resisting dominant ideologies, and older adults may use leisure to resist ageist stereotypes, leading to feelings of empowerment. Since persons with dementia experience increased stigma, leisure may be a space to resist stereotypical notions of dementia. This paper explores leisure as a space for resistance and presents a research agenda for researchers to better understand the political nature of leisure within the context of dementia.

Keywords: ageism, stigma, dementia, resistance, aging

Just dance with me: An authentic partnership approach to understanding leisure in the dementia context

Dupuis, S. L., Whyte, C., Carson, J., Genoe, R., Meshino, L., & Sadler, L. (2012). Just dance with me: An authentic partnership approach to understanding leisure in the dementia context. *World Leisure Journal*, 54(3), 240-254. doi:10.1080/04419057.2012.702454

Most research on marginalised groups, including those living with illness or disability, continues to exclude those experiencing illness or disability from decision making in the research endeavour. This is particularly true for persons living with dementia, who are stigmatised, misunderstood and assumed to lack the capacity to actively participate in all aspects of the research process. In this paper, we provide a detailed account of one collaborative project, an innovative participatory action research (PAR) project that brought together persons living with dementia, family members, recreation professionals from a range of settings (i.e., the community, day programmes, long-term care homes), Alzheimer Society staff and researchers as we worked together to consider the notion of leisure and its meanings for persons living with dementia. We describe the PAR cycles of planning, acting/observing and reflecting on what we have completed thus far; share our reflections on the process, including our struggles and insights on the possibilities of the approach; and present what we have learned from our partners with dementia about how we can better support them in similar processes.

Keywords: dementia, authentic partnerships, participatory action research, meanings of leisure

Rethinking sociability in long-term care: An embodied dimension of selfhood

Kontos, P. (2012). Rethinking sociability in long-term care: An embodied dimension of selfhood. *Dementia*, 11(3), 329-346. doi:10.1177/1471301211421073

Sociability, interaction through which solitariness becomes togetherness or a union with others, has largely been explored without reference to the importance of bodily sources of agency. Encapsulated in the theoretical notion of embodied selfhood is the pre-reflective nature of selfhood deriving from the body's pre-reflective capacity for engaging with the world and the socio-cultural significance of the body. This paper argues for an expansion of the discourse on sociability in dementia to include embodied selfhood as a source of interactive practices. An 8-month ethnographic study of selfhood in dementia was conducted in a Canadian long-term care facility. The findings suggest that social and cultural habits, movements and other physical cues serve important communicative functions in the course of social interaction. This underscores how sociability is an embodied dimension of selfhood, which not only broadens the discourse on sociability in dementia but also offers important insights to inform person-centred dementia care.

Keywords: dementia, embodiment, selfhood, sociability, social interactions

An evaluation of a therapeutic garden's influence on the quality of life of aged care residents with dementia

Edwards, C., McDonnell, C., & Merl, H. (2013). An evaluation of a therapeutic garden's influence on the quality of life of aged care residents with dementia. *Dementia*, 12(4), 494-510. doi:10.1177/1471301211435188

To evaluate whether a therapeutic garden can improve the quality of life of aged care residents with dementia and their carers, objective instruments as well as interviews with residents, staff, and family members were employed. Residents' mean quality of life scores increased by just over 10%, mean depression scores decreased similarly and mean agitation scores decreased by almost half. Resident, staff and family member interviews elicited positive feedback including observations that it had improved the quality of life for residents and decreased staff and family stress levels. In sum, qualitative and quantitative pre and post findings indicate that an environmental change such as a therapeutic garden can improve the lives of aged care residents with dementia, and their formal and informal carers.

Keywords: agitation, dementia, garden, quality of life, residential facilities

iPods® for memories program

Sears, J. (2014). iPods® for memories program. *Therapeutic Recreation: Practice & Research Journal of Therapeutic Recreation Ontario*. 9, 8-19.

The following paper outlines the iPods® for Memories program implemented in two facilities for older adults in January 2013 by the Alzheimer Society of Huron County. An iPod®-focused program can provide a valuable music intervention uniquely tailored for each client through the use of personalized music playlists. Specific client goals such as enhancement of self-identity or providing an opportunity for positive engagement may also be addressed. Finally, an iPod®-focused music program can also facilitate modulation of client affect – acting as a positive

redirection for aggressive behaviour, a mood enhancer for depressive behaviour, or a focusing technique for chronic anxiety. For the recreation therapist, an iPod®-focused music program offers flexibility and efficiency in meeting a wide variety of client goals with a singular intervention tool. While iPod®-focused music programs have been documented in terms of success with clients exhibiting agitated behaviour, I find it an effective method for addressing another common behavioural component of dementia: apathy. The literature review in this article supports my rationale for using an iPod®-focused music program as an intervention to address apathy in late stage dementia. I will define apathy, discuss methods for measuring aspects of engagement, and address the effectiveness of using personalized stimuli to enhance the client's quality of life. Finally, I will present my experience with using the iPods® for Memories program, followed by a discussion and some recommendations for practice.

Keywords: apathy, engagement, personalized stimuli, individualized music, dementia, late stage dementia

The role of leisure within the dementia context

Genoe, M., & Dupuis, S. (2014). The role of leisure within the dementia context. *Dementia*, 13(1), 33-58. doi:10.1177/1471301212447028

While our understanding of the subjective experience of dementia is growing, leisure's role within that experience is less clear. This study, guided by hermeneutic phenomenology, aimed to understand the meaning and experience of leisure for persons living with early stage memory loss. Four participants with early stage dementia participated in interviews, participant observation, and photovoice, in which participants are given cameras and asked to take photos of their day to day lives (Wang, 1999). Data revealed that participants experienced daily life with dementia, including leisure, within a paradox of challenge and hope. They struggled with the changes they experienced as a result of dementia, such as muddled thinking, fluctuating abilities, draining energy, frightening awareness, and disquieting emotions. However, they found ways to tackle life with dementia, by reconciling life as it is, battling through by being proactive, living through relationships, being optimistic, and prolonging engagement in meaningful activity to live their lives with hope.

Keywords: Alzheimer's disease, dementia, leisure, phenomenology, photovoice

Bringing home to long-term care: The impact of one's environment in building a sense of community and promoting wellbeing

Hercules, T., & Ashby, J. (2015). Bringing home to long-term care: The impact of one's environment in building a sense of community and promoting wellbeing. *Therapeutic Recreation: Practice & Research Journal of Therapeutic Recreation Ontario*. 10, 1-12.

Creating a more home-like environment was put on the forefront when Therapeutic Recreation (TR) staff of the long-term care (LTC) Mental Health Support Unit at Baycrest realized that common areas were not being utilized by residents, which led to further examination: Why were residents not using these spaces? How can we make residents feel more at home? What does "home" mean, especially in long-term care? Inspired by Montessori methods for dementia approaches (Elliot, 2012), a collaborative project was created and led by the unit TR staff in reallocating and re-designing unused space for the residents. Further research of this topic as well as facilitating resident focus groups, allowed TR staff to more clearly define the need for change in the physical environment, in hopes of creating more possibilities for interaction and a sense of community.

Keywords: long-term care, physical environment, culture change, wellbeing, Montessori Methods for Dementia, supportive environments

Sharing the journey: Exploring a social leisure program for persons with dementia and their spouses

Fortune, D., & Mckeown, J. (2016). Sharing the journey: Exploring a social leisure program for persons with dementia and their spouses. *Leisure Sciences*, 38(4), 373-387. doi:10.1080/01490400.2016.1157776

In this article, we highlight the marginalization and exclusion persons with dementia and their spouses often face in leisure practices and spaces. We then explore aspects of a peer-led community social program aimed at inclusion. Framed in creative analytic practice, the experiences of members of the social program are shared through a composite narrative. This narrative tells the story of a couple from the point of diagnosis who seek support and education and eventually find deep social connections with others who are on a shared journey. We draw from this narrative to explore meanings of inclusion for spousal couples on the dementia journey and use a social justice lens to consider how to address experiences of exclusion in leisure practices and spaces.

Keywords: creative analytic practice, dementia, inclusion, narrative, social justice

The relationship between apathy and participation in therapeutic activities in nursing home residents with dementia: Evidence for an association and directions for further research

Ellis, J. M., Doyle, C. J., Selvarajah, S.(2016). The relationship between apathy and participation in therapeutic activities in nursing home residents with dementia: Evidence for an association and directions for further research. *Dementia*, 15(4), 494-509. doi:10.1177/1471301214527300

Apathy is one of the most frequent and early symptoms of dementia. Because apathy is characterised by lack of initiative and motivation, it leads to considerable burden being placed on carers to ensure that the person living with dementia has a reasonable quality of life. The aim of this study was to investigate the relationship between apathy and participation in therapeutic activities for older people with dementia living in nursing homes. Ninety residents were recruited into the study, and apathy was measured by nursing home staff using the Apathy Evaluation Scale Clinician version. Staff also compiled data on each resident's involvement in therapeutic activities. Among this sample, the mean age was 84.8 years, and mean length of stay in the nursing home was 1.8 years. The mean apathy score was 50.4, indicating that on average the residents had a moderate level of apathy. Overall, residents participated in six activities per week and those residents who were involved in the most activities had the lowest levels of apathy. This paper provides evidence that residents involved in therapeutic activities have lower levels of apathy. Further research should be conducted on the direction of causality, whether apathy levels can be changed through participation in therapeutic activities, the relationship between dementia severity and modifiability of apathy, and the intensity of therapeutic activities required to maintain functioning.

Keywords: Apathy Evaluation Scale, apathy, dementia, nursing homes, therapeutic activities

Re-claiming citizenship through the arts

Dupuis, S. L., Kontos, P., Mitchell, G., Jonas-Simpson, C., Gray, J.(2016). Re-claiming citizenship through the arts. *Dementia*, 15(3), 358-380. doi:10.1177/1471301216637206

Healthcare literature, public discourse, and policy documents continue to represent persons with dementia as “doomed” and “socially dead.” This tragedy meta-narrative produces and reproduces misunderstandings about dementia and causes stigma, oppression, and discrimination for persons living with dementia. With few opportunities to challenge the dominant discourse, persons with dementia continue to be denied their citizenship rights. Drawing on the concept of narrative citizenship, we describe a community-based, critical arts-based project where persons with dementia, family members, visual and performance artists, and researchers came together to interrogate the tragedy discourse and construct an alternative narrative of dementia using the arts. Our research demonstrates the power of the arts to create transformative spaces in which to challenge dominant assumptions, foster critical reflection, and envision new possibilities for mutual support, caring, and relating. This alternative narrative supports the reclamation of citizenship for persons living with dementia and fosters the relational citizenship of all.

Keywords: dementia, narrative citizenship, critical arts-based research, relationality, embodiment

The meaning of music in sustaining relationships for individuals with dementia and their families: A case study in long-term care

Colwell, M., & Whyte, C. (2016). The meaning of music in sustaining relationships for individuals with dementia and their families: A case study in long-term care. *Therapeutic Recreation: Practice & Research Journal of Therapeutic Recreation Ontario*. 11, 88-98.

Within LTC homes, the most common form of treatment for symptoms associated with dementia involve pharmacological interventions. Growing interest in less medicalized, person-centered approaches have led practitioners and researchers alike to explore the use of creative therapies to address responsive behaviours and maintain a sense of self. Programs involving the use of music have been shown to produce an array of personal benefits such as improvements in attention and cognition, and increased social interaction. This paper examines the contribution of co-participation in a 4-week structured music program on the relationship between a resident living with dementia in a LTC home and her family member. Music programming was selected as an intervention because it provides an opportunity for participants to utilize alternative communication skills and foster social connections with others (Rylatt, 2012). Analysis of our conversations with Vivian and Brea led us to identify three themes within our research: witnessing the power of music, inspiring deeper connections and experiencing more meaningful visits. Each speaks to the unique qualities of music and its ability to draw on past memories and experiences, ultimately enhancing one’s quality of life.

Keywords: music programming, family involvement, dementia, long-term care home

“It makes me feel like myself”: Person-centered versus traditional visual arts activities for people with dementia

Sauer, P. E., Fopma-Loy, J., Kinney, J. M., Lokon, E. (2016). “It makes me feel like myself”: Person-centered versus traditional visual arts activities for people with dementia. *Dementia*, 15(5), 895-912. doi:10.1177/1471301214543958

During a 15-month period between February 2010 and April 2011, video data on (n = 38) people with dementia were collected during a person-centered and intergenerational arts activity program called Opening Minds through Art (OMA) at three different long-term care facilities in Ohio. A subsample of the OMA participants (n = 10) were also video recorded during traditional visual arts activities (e.g. coloring books, scrapbooking). A modified version of the Greater Cincinnati Chapter Well-Being Observation Tool© was used to code the intensity and frequency of observed domains of well-being (i.e. social interest, engagement, and pleasure) and ill-being (i.e. disengagement, negative affect, sadness, and confusion). Descriptive results indicate a high percentage of moderate or high intensities of well-being during OMA sessions with little to no ill-being. Paired-sample t-tests comparing OMA vs. traditional visual arts activities showed significantly higher intensity scores for OMA in the domain of engagement and pleasure, as well as significantly lower intensity scores for disengagement. The findings of this exploratory study contribute to the overall discussion about the impact of person-centered, creative-expressive arts activities on people with dementia.

Keywords: Alzheimer’s disease, arts activities, creativity, creative self-expression, dementia, quality of life, well-being

Honouring personhood in LTC: Lessons from family

Keszthelyi, K., & Whyte, C. (2016). Honouring personhood in LTC: Lessons from family. *Therapeutic Recreation: Practice & Research Journal of Therapeutic Recreation Ontario*. 11, 78-87.

The purpose of this research was to understand the ways in which personhood is honoured by family of an individual with advanced dementia living in a LTC home. With the support of staff

at the home, we interviewed a husband whose wife lived at Sunnyvale LTC home in Southern Ontario. Using a case study approach, we explored how Sunnyvale staff came to know and support John and Agatha (pseudonyms) and how John was able to enrich staff's knowledge of Agatha through his active involvement and presence in her life. After thematic analysis by both authors, we concluded that family members are the defender of personhood by advocating personhood, preserving personhood and being a companion in personhood. As TR practitioners, we are in a crucial position to enhance personhood by working with family members and including them in meaningful experiences within LTC, thus enabling families to continue to be involved in the life of their family member.

Keywords: dementia, personhood, long-term care, role of family, quality of living