

Running head: COMPARISON OF QUALITY OF LIFE IN DEMENTIA

Comparison of Quality of Life of Older Adults Living in a Licensed Dementia Housing

Facility to Community Dwelling Older Adults with Dementia

Research Proposal

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Psychology 490

Comparison of Quality of Life of Older Adults Living in a Licensed Dementia Housing Facility to Community Dwelling Older Adults with Dementia

There is a momentous need for research pertaining to older adults with dementia (Hyde, Perez, & Forester, 2007). This research is especially pertinent since it is estimated that in 2026, one in five Canadians will have reached the age of 65, and the two most common mental health problems encountered by older adults are that of dementia and depression (Health Canada, 2002). In our aging population, home may be where most people wish to live out their years. For older adults that have dementia, home may not always be a realistic option (Riemer, Slaughter, Donaldson, Currie, & Eliasziw, 2004). In Canada, over half of all older adults with dementia live in institutions (Canada Study of Health and Aging, 1994). The other half of older adults with dementia most commonly live at home with help of an informal caregiver (Drunkelman & Dressel, 1994). Deciding whether to place a loved one in a nursing home is often the most difficult decision informal caregivers for older adults with dementia have to face (Kaplan, 2003).

Informal caregivers are generally defined as persons who help a relative or friend, without pay, with one or more instrumental and/or basic activities of daily living (Bertrand, Fredman, & Saczynski, 2006). Informal caregivers and other members of the social support system of older adults with dementia are shown to struggle with increased feelings of guilt, anger, and terror as they attempt to provide care for their loved one who is tumbling down the spiral of dementia (Drunkelman & Dressel, 1994).

Family members frequently make great sacrifices to provide what they see as an ideal quality of environment for their afflicted loved one (Drunkelman & Dressel, 1994). Most individuals with Alzheimer's disease are cared for at home by their family members for much of

the course of their illness (Drunkelman & Dressel, 1994). Family members of persons with dementia are faced with how to best care for their loved one, while keeping them as active and independent as possible (Moriarty, 2007). Given current demographic and health care trends, we can expect to see an increase not only in the overall number of informal caregivers but also in the proportion of those caring for adults with dementia (Brookmeyer & Gray, 2000).

Alzheimer's disease, the most frequent cause of dementia, can last from 2 to 22 years (Hellman, 2006). Adults with dementia invariably develop both functional and cognitive impairments which predispose them to behavioral symptoms, the loss of intellectual capacity, personality functioning, as well as the loss of the ability to communicate their wants and needs (Hellman, 2006). During the course of dementia, both the individual with dementia and their families go through a series of role changes and transitions (Drunkelman & Dressel, 1994). Caring for a friend or relative with Alzheimer's disease or any other form of dementia is stressful for reasons beyond those directly involved with cognitive or behavioural changes (Bertrand et al., 2006). In particular, caregivers of older adults with dementia must cope with the reality that their loved ones are facing an irreversible and degenerative disease that will increasingly steal from the caregiver the emotional and intellectual reciprocity that they once shared with their loved one (Bertrand et al., 2006). The informal caregiver of the individual with dementia has the option to continue caring for their loved one at home or to place their loved one in an Assisted Living facility.

Assisted living is generally described as part of a continuum which begins with individuals living independently at home and concludes with clients moving into residential care facilities (Langford, 2007). A central aspect of the Assisted Living philosophy is that of a respect for the individuals who live in this setting and their continued rights as human beings and citizens (Hyde et al., 2007). In Assisted Living settings, the provision of good quality care by well-trained staff can enable older adults with dementia to do as much as possible for

themselves, while also offering appropriate support with tasks that they can't manage on their own (Moriarty, 2007). Moriarty (2007) showed that many Assisted Living facilities are equipped with day programs for their clients that may help promote independence by providing activities that aid rehabilitation and maximize physical and cognitive function. On the whole, extra care housing can maximize the opportunities for people with dementia to live independent lives (Moriarty, 2007).

Caregivers in Assisted Living, as well as caregivers in the home situation, strive to offer the best possible quality of life to those they care for (Dröes et al., 2006). Yeh, Johnson, and Wang (2002) found that four months after placement in a long-term care facility, global burden on caregivers decreased due to vast improvements in family support, scheduling, and physical health. A recent longitudinal study compared quality of life of residents at specialized dementia care facilities with residence at traditional institutional long-term care over a 1-year period (Riemer et al., 2004). The findings of this study suggest that the quality of life for adults with middle to late-stage dementia is the same or better across time in a specialized dementia care facility than in traditional long-term care institutional facilities (Riemer et al., 2004).

Vancouver Island Health Authority (VIHA) has recognized that older adults with mild-moderate levels of dementia cannot always function safely in standard Assisted Living settings (MacCourt, 2008). Older adults with dementia generally require higher levels of supervision and assistance than is consistently possible in most Assisted Living settings (MacCourt, 2008). In addition, the Community Care & Assisted Living Act of 2002 (Community Care and Assisted Living Act, 2002) has placed stringent restrictions on the capability of adults with mild to moderate dementia to enter or – if already resident – to continue residing in Assisted Living. As a result, adults with mild to moderate dementia frequently move into Residential Care facilities,

which is the only housing alternative when their informal and formal caregivers can no longer maintain them in their own home (MacCourt, 2008). In many instances, the level of care provided in Residential Care facilities is perceived by service providers as higher than needed for these adults (MacCourt, 2008). The physical environment of a health care facility for older adults with dementia should support as wide a range of behaviors as possible, yet the design of most nursing homes is not able to accomplish this (Drunkelman & Dressel, 1994).

Licensed Dementia Housing (LDH) facilities are newly commissioned settings that support individuals with mild to moderate dementia who cannot remain in their own home due to the effects of their dementia but who are also not eligible for other forms of housing or Assisted Living (MacCourt, 2008). LDH facilities are designed to be a bridge between Assisted Living and Residential Care facilities for adults with dementia (MacCourt, 2008). LDH facilities are completely devoted to care of individuals with dementia, and practice in dementia care (MacCourt, 2008). LDH facilities are potentially more 'homely' alternatives to residential and nursing home care for older adults with dementia (Heywood, Oldman, & Means, 2002). One of the main attractions of extra care may be the 'home for life' philosophy, which aims to promote independence for people with high levels of frailty in a supported environment, thus reducing moves to other care settings (Evans, Fear, Means, & Vallyelly, 2007).

The overarching goal for LDH facilities is to provide a cost-effective alternative to Residential facility care (MacCourt, 2008). LDH facilities are designed to assist individuals who do not meet the legislated criteria for Assisted Living and who are also assessed to not need the full suite of services provided in residential care facilities (MacCourt, 2008). LDH facilities will provide evidence for whether a secure, best practice, community orientated, dementia care

program can support clients to remain in a community living setting for longer than they might if they were to remain at home (MacCourt, 2008).

A recent summary of a LDH facility on Vancouver Island has shown that the model of care used at this facility reflects the best practices in dementia care identified in the literature (MacCourt, 2008). In this summary, the families of the clients at this LDH facility have also reported a high degree of satisfaction in both the effectiveness of quality of care provided (MacCourt, 2008). This recent literature on LDH facilities explores the setting and care of clients at LDH; however, there is still a vacancy in the literature regarding the client's quality of life when compared to their peers in the community.

Since LDH facilities have only recently been established in 2007 (MacCourt 2008), the comparison with community-dwelling individuals with dementia is clearly the next research step to take. This study will assist in filling the void of literature pertaining to older adults with dementia and the most compatible living environments for their own health, as well as the health of their formal and informal caregivers.

There are few empirical studies relating components of long-term care to quality of life for residents with dementia (Zimmerman, Sloane, Williams et al., 2005). Overall, there has also been scarce research examining what type of environment works best for people with dementia (Langford, 2007). This study will add to the limited knowledge obtained thus far on the quality of life that individuals with dementia experience in different living situations.

Presently, more adults are turning 65 than at any other time in history (Moriarty, 2007). Consequently, more individuals are faced with someone close to them developing dementia. The purpose of this study will be to answer what every family member and friend of someone with

dementia will ask: Do individuals in a LDH facility have the same quality of life as those who stay at home with a family caregiver?

This context of care in caring for some with dementia is unique. Caring for someone with dementia involves a grieving process for the family caregivers as well as the care receiver is incapable of making decisions about his or her own care (Caron, Griffith, & Arcand, 2005).

Once an individual reaches the later stages of dementia, the ability to make decisions about their care is lost, and family members are often called upon to participate in decisions about treatment on behalf of their loved one. (Caron, Griffith, & Arcand, 2005)

As Drunkelman and Dressel (1994) have shown in their research, family members and informal caregivers make vast sacrifices to ensure their loved one with dementia is cared for. If individuals in a LDH facility are shown to experience a similar quality of living to individuals with dementia who reside in their own homes, caregivers may be more willing to place their loved one in a LDH. This will decrease the caregiver's burden, which could lead to improved overall health of the caregiver (Yeh et al., 2002). The information collected in this study will be invaluable to caregivers of individuals with dementia who do not want their loved ones to be placed in a regular long-term care facility, but are finding the burden of caregiving to be debilitating. This study will examine the quality of life of residents of LDH facilities compared to a similar population of individuals with dementia who are residing at home, in the community, with the aid of a family care giver.

Methods

Participants

There are two sets of participants that were recruited for this study. The first set of participants were nine residents with moderate dementia who are residing in a Licensed Dementia Housing facility on Vancouver Island (LDHF). The study also recruited formal caregivers who are employed at the LDHF and who have regular contact with the LDHF residents participating in this study.

The second set of participants is comprised of 11 community-dwelling Vancouver Island residents who have mild to moderate cognitive impairment who live at home with the help of an informal caregiver. This study also interviewed the informal caregiver for each of the older adults with dementia residing in the community.

Design

This study uses a between-participant design to compare the quality of life of individuals with mild to moderate dementia who are residing in a LDHF to individuals with mild to moderate dementia who are residing in the community with the support of a family caregiver.

The Folstein Mini-Mental Status Examination (MMSE; Appendix A) was administered to both groups, LDHP and the community dwelling participants. Quality of life was measured using the Pleasant Events Schedule (PES; Appendix B) and the Cornell Scale for Depression in Dementia (CSDD; Appendix C). Comparisons between the two groups was be made through the use of t-tests and the Mann-Whitney-U test for nonparametric statistics.

Measures

The Pleasant Events Schedule (PES-AD; Teri, Logsdon, Uomoto, & McCurry, 1997).

The PES-AD is a caregiver-report questionnaire designed to identify pleasant events for Alzheimer's disease patients (Logsdon, & Teri, 1997). This questionnaire includes a list of potential pleasant events in which individuals with dementia may engage (Logsdon, & Teri, 1997). The PES-AD asks caregivers to rate whether the individual with dementia now takes pleasure in each activity, whether the individual with dementia enjoyed it in the past, and how regularly they engaged in each activity during the previous month (Logsdon, & Teri, 1997). The PES-AD was demonstrated to have good internal consistency ($\alpha=.90$) and to correlate with severity of depression in AD patients (Logsdon, & Teri, 1997).

The Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, Abrams, Young, & Shamoian, 1998). The CSDD was specifically developed to assess signs and symptoms of major depression in patients with dementia (Alexopoulos et al., 1998). Since some of these patients may give unreliable reports, the CSDD uses an inclusive interviewing approach that derives information from the patient and the informant (Alexopoulos et al., 1998). Information is obtained with the CSDD through the use of two semi-structured interviews: an interview with an informant and an interview with the individual with dementia (Alexopoulos et al., 1998).

Folstein Mini-Mental Status Examination (MMSE; Folstein, Folstein & McHugh 1975).

This questionnaire is a widely accepted and internationally recognized questionnaire (Galasko, Abramson, Corey-Bloom & Thal, 1993). The MMSE a quick and easy measure of cognitive functioning that has been widely used in clinical evaluation and research involving patients with dementia (Folstein, Folstein & McHugh 1975). The MMSE has high test-retest reliability values, ranging from 0.79 to 0.9 (Galasko et al., 1993).

Procedure

Participants in the CDP and their family caregivers were interviewed at a convenient location of their choice, including their home or a coffee shop. This study administered the MMSE to participants with mild to moderate dementia. The caregiver portion of the CSDD was then administered to the family caregiver. The caregiver was also asked to complete the PES-AD

Participants of the LDHP group and their formal caregivers were interviewed on site at the LDHF. The residents of the LDHF were administered the MMSE by the student researcher, if a health care provider had not administered this test, and received a score, in the last six months. A formal caregiver who had regular contact (5 days a week) with the client completed the caregiver portion of the CSDD. The formal caregiver also completed the PES-AD.

Results

Total amount of participants interviewed was 20 individuals with dementia and their formal or informal caregivers. Age, and education, of participants with dementia was not significantly different between the two groups. The Median score on the MMSE for community dwelling participants with dementia was 18 (Range 2-28). The Median score for participants at the LDHF was 16 (Range 10-23). A score below 20 on the MMSE indicates high likelihood of dementia (Folstein, Folstein & McHugh 1975).

A greater number of pleasant events were experienced by participants residing in the LDHF compared to community dwelling participants ($p < .05$). As well, greater enjoyment in pleasant events was reported by participants residing in the LDHF compared to community dwelling residents as measured by the Pleasant Events Schedule ($p < .05$). The results from the PES were analyzed using t-tests which compares the means of two independent groups. These findings are shown on Figures one and Figures two.

As shown in Figure Three participants in the community dwelling group were found to have more depression, as measured by the CSDD, than residents of the LDHF. Although a difference was found when analyzing the CSDD scores, this difference was not statistically significant ($p = .051$). The results from the CSDD were compared using the Mann-Whitney-U test which compares the medians of two independent groups. We believe that with a larger samples size a statistical difference would be found in community dwelling individuals with dementia and residents of the LDHF in the CSDD.

Discussion

Caregiving to a friend or relative with dementia is a stressful situation (Bertrand, Fredman, Saczynski, 2006). The movement from a community dwelling situation to a long term care facility is a major life event for both the individual with dementia and their informal caregiver (Buhr, Kuchibhatla, & Clipp, 2006). There often is little knowledgeable direction from health care providers (Buhr, Kuchibhatla, & Clipp, 2006). Guidance and knowledge in this area would help to increase the chances for appropriate and timely nursing home placement, which would not only benefiting the patient but also reducing caregiver guilt and stress over these issues (Buhr, Kuchibhatla, & Clipp, 2006).

The premise underlying this study was to discover if older adults with dementia have a greater quality of life when compared to older adults with dementia who are still living in the community and are taken care of by an informal caregiver. The results of this study support the hypothesis that older adults with dementia are happier in a LDHF when compared to a similar population of older adults in the community with dementia, with the help of their informal caregivers when it is time to make a decision on placing their loved on in a long term care facility. The information found in this study will be able to be disseminated to the families and informal caregivers of community dwelling individuals with dementia. The information found in this study will help educate informal caregivers and their service providers with the very difficult decision of whether to place their loved one in a facility.

Being that Licensed Dementia Housing Facilities are newly commissioned settings (MacCourt, 2008), health care providers may not be fully informed as to the quality of care that is provided in one of these facilities; and thus they would be unable to fully guide the caregivers

in their decision to place their loved on in such as facility. The findings of this study will aid health care providers who are in positions to influence a caregiver's decision for placing their loved on in a facility. This information found in this study will also empower health care providers to discuss the issue and thus take some of the guilt and burden from caregivers.

When compared to non-dementia caregivers, caregivers to older adults with dementia report higher stress, more care recipient problems, greater caregiving intensity, and greater feelings of captivity in the caregiving role (Bertrand, Fredman, Saczynski, 2006). Furthermore, given that the average age of the informal caregivers in this study is 70 years these individuals are already managing all the health issues that coincide with an aging population; the additive stress and the physically demanding aspects that coincide with the caregiver role may turn out to be the breaking point for the informal caregiver's mental and physical health (Bertrand, Fredman, Saczynski, 2006).

This study has some weaknesses that should be noted. First, it was conducted in a sample of predominately White, older adults with dementia. The results may not be generalizable to middle-aged and non-White individuals with dementia. Another limitation is that the results are based on cross-sectional data. A longitudinal study that includes two or more time points for data collection would allow for the examination of change in quality of life as time goes on and the dementia progresses in both the quality of life of older adults in the LDHF, and the quality of life of older adults in the community.

Future research should explore the quality of life of the formal caregivers in the LDHF to the informal caregivers in the community. This would allow for the comparisons of the mental and physical health of individuals caring for a similar population but in two different settings. Future research should also examine the quality of life in standardized long term care facilities.

This would allow for a comparison between the quality of life between older adults with dementia in the community, in a standardized facility, and in a LDHF to be made.

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Figure Caption

Figure 1. Mean number (\pm SEM) of pleasant events experienced by community dwelling and Licensed Dementia Housing Facility (LDHF) residents . Pleasant events were measured by the Pleasant Events Schedule. Residents of the LDHF reported higher frequencies of pleasant events, $t(18) = -3.107, p < .05$.

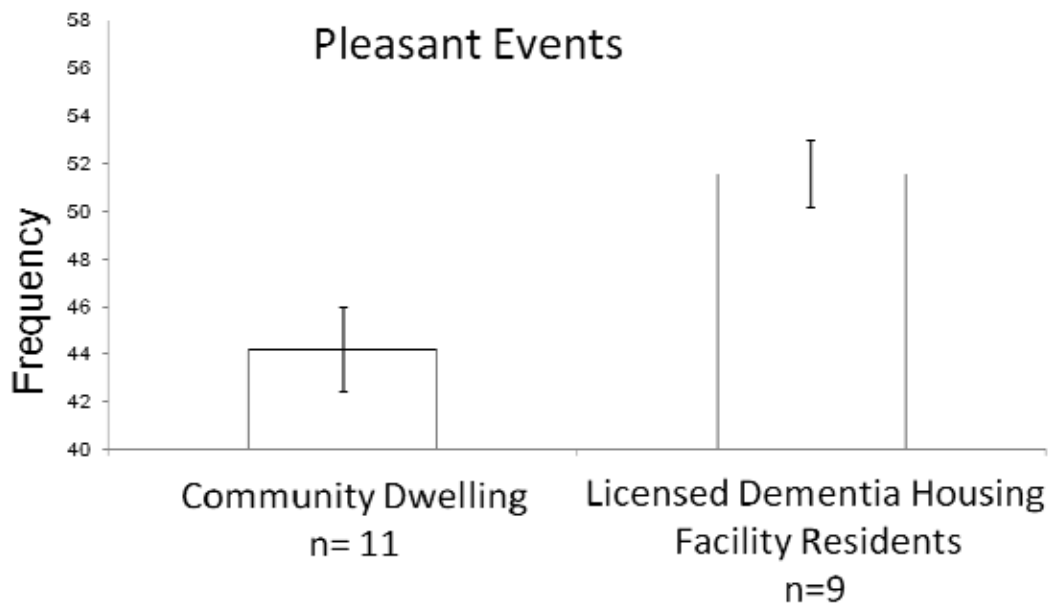


Figure Caption

Figure 2. Average amount (\pm SEM) of enjoyment experienced during pleasant events by community dwelling and Licensed Dementia Housing Facility (LDHF) residents. Pleasant events were measured by the Pleasant Events Schedule. Residents at the LDHF reported greater enjoyment of pleasant events, $t(14.1) = -3.087, p < .05$



Figure Caption

Figure 3: Median depression scores (\pm interquartile range) of participants as reported by the primary (formal or informal) caregivers measured by the Cornell Scale for Depression in Dementia. Although a difference was found, this difference was not statistically significant ($p = .051$).

