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# The Influence of Occupational Therapy on Quality of Life for Individuals with Dementia Living at Home in the Community: A Literature Review

## **Abstract**

### *Background*

Dementia is the broad term used to describe a range of conditions, which effect the function of the brain. In addition to behavioural, emotional and social changes, dementia has a progressive decline in functional abilities (Cummins and Warren 2010; Olazarán *et al* 2010). As the prevalence of dementia diagnoses rise; the demands for occupational therapy services will escalate (Perrin *et al* 2008).

### *Objectives*

To review the literature to establish current occupational therapy interventions for individuals with mild to moderate dementia and to ascertain the influence on quality of life and wellbeing for individuals with mild to moderate dementia who are living at home in their communities

### *Methods*

The following databases were searched (AMED, Cinahl, Cochrane Library, MEDLINE, PsycARTICLES, PsycInfo, PubMed, UK & Ireland Reference Centre) for literature since 2005.

### *Findings*

Over 1900 studies found. However, only three papers (Graff *et al* 2007b; Lam *et al* 2010; Voigt-Radloff *et al* 2011) specifically addressed quality of life for individuals with dementia in the community. Their findings were mixed regarding the influence occupational therapy has on quality of life.

### *Conclusions*

Recent years have seen an increase in the literature for occupational therapy in dementia care. However, current research focuses mainly on caregiver burden and behaviour difficulties with limited research investigating the relationship occupations have in influencing the well-being or quality of life of the individual with dementia. Further research needs to investigate the complexities of wellbeing and quality of life for individuals with Dementia.

Keywords: Occupational Therapy, Dementia, Quality of Life, Wellbeing.

## **Introduction**

As the prevalence of dementia diagnoses rises, the demands for occupational therapy services will escalate (Perrin et al 2008). It is estimated that 35.6million people worldwide are living with dementia and this is expected to rise by 71% by 2050 (WHO 2012). In Ireland, dementia affects approximately 15% aged 65 years and 30% aged 80 years. Many appear to live on average eight years following initial diagnosis, although individuals can live up to twenty years from the onset of symptoms (O'Connor 2011). It has been proposed that there are up to 4000 new diagnoses in Ireland annually (O'Shea 2007) and most individuals with dementia are living in the community (Cahill 2012; Cahill *et al* 2012; O'Connor 2011). Although dementia mainly affects older adults, it is not an element for the normal ageing process (Alzheimer Association 2013; WHO 2012). Dementia is the broad term used to describe a range of conditions which effect brain function and symptoms can include: memory decline, communication and language difficulties, behaviour problems, decreased social skills, changes in mood and personality as well as a decline in hobbies and interests (Alzheimer Association 2013; Cahill *et al* 2012; DSIDC 2013; O'Shea 2007, The Alzheimer Society of Ireland 2013; WHO 2012). In addition to behaviour, emotional and social changes, there is a decline in functional abilities (Egan *et al* 2006; Cummins and Warren 2010; Graff *et al* 2006; Miller and Butin 2000; Olazarán *et al* 2010; Warren 2005). Due to the profound effect dementia has on daily living it is pertinent to establish the influence on wellbeing and quality of life.

## **Literature Review**

According to Anderson *et al* (2011) human beings place great emphasis on achieving what is perceived to be happiness and wellbeing and the term 'Quality of Life' has grown among health researchers to ascertain evidence basis for therapy interventions (Farquhar 1995; Felce 1997; Kaplan and Ries 2007). Although defining the term appears challenging (Barofsky 2012; McKevitt *et al* 2003), Ferrell (1995) defines 'quality of life' as four components under wellbeing: physical, mental, social and spiritual. This resonates with occupational therapy's holistic approach, considering all aspects of the individual, addressing what is most meaningful to them, as opposed to just the impairment (Townsend and Polatajko 2007). Furthermore, according to the NHS Scotland (2006) wellbeing is an accumulation of a number of factors that include positivity, being in control, satisfaction with life, purposefulness in life, feeling supported and that you belong.

Occupational therapy is centred on an ethos that health and wellbeing are promoted through engaging in occupations (Townsend and Polatajko 2007, Wilcock 2006), which encompass everything individuals do to occupy themselves, including; self-care, recreation, work and employment (Townsend and Polatajko 2007). Research has highlighted this positive relationship between health and wellbeing and occupational therapy interventions (Clark *et al* 1997; Mountain *et al* 2008). Occupational therapy in dementia care includes; daily living activities (Graff *et al* 2006 and 2007a/b; Miller and Butin 2000; Voigt-Radloff *et al* 2011), functional independence (Burton 2003; Miller and Butin 2000), social engagement (Graff *et al* 2006 and 2007a/b) and health and wellbeing promotion (Egan *et al* 2006; Graff *et al* 2007b; Miller and Butin 2000; Voigt-Radloff *et al* 2011; Warren 2005). Recently Dutch researchers have formulated the Community Occupational Therapy in Dementia Program (COTiD), consisting of ten one-hour sessions over a five week period. The sessions address occupational issues of the individual with dementia and include considerations for the caregiver (Graff *et al* 2006).

Several studies illustrate the complex needs of individuals with dementia (Burton 2003; Egan *et al* 2006; Lee *et al* 2006). Daily challenges have been identified such as memory loss, executive functioning difficulties and fatigue, which influence occupational engagement (Lee *et al* 2006). There is also evidence that suggests individuals with dementia have insight and some awareness of the impact the illness has on their daily life (Öhman *et al* 2008). The research also demonstrates that occupations remain highly valued (Egan *et al* 2006) and occupational priorities include maintaining independence with tasks (Burton 2003) and social interactions (Öhman *et al* 2008). There is a critical need for early intervention to assist individuals and enable them to cope with their declining abilities (Lee *et al* 2006).

These studies highlight the essential role occupational therapy has to play in dementia care; however, it would seem that many therapists report having little knowledge of dementia care (Perrin *et al* 2008). Although research by Cummins and Warren (2010) demonstrated the extensive practice of occupational therapists in the Irish dementia care setting, their research also highlighted the bureaucratic challenges faced by therapists due to the current provision of services. At present the Dementia care services in Ireland appear limited and under-developed (Cahill 2010; Cahill *et al* 2012) highlighting the imperative need for evidence-based interventions to advocate for the allocation of service provisions.

This research project will review the literature in attempt to establish what interventions occupational therapists are currently conducting with individuals who have mild to moderate dementia and to ascertain the influence occupational therapy has on the quality of life and wellbeing for individuals with mild to moderate dementia living at home in their communities.

## **Methodology**

The increasing demand for treatment and intervention therapies derived from scientific evidence (Rappolt 2003) has resulted in literature reviews imperative role in healthcare research (Loke *et al* 2007; McIntosh *et al* 2004). A review communicates the results and findings of scientific literature, studies and/or clinical trials following a specific intervention, treatment or method. The research is evaluated, critically appraised and summarised. (Green 2005; Ng and Peh 2010). Individual studies are combined thus promoting the reliability of the research while in addition improving the accuracy of recommendations made and limiting bias (Ng and Peh 2010).

This project looked at research that was conducted since 2005. A recent systematic review by Letts *et al* (2011) aimed to investigate what effect interventions that modified or adapted occupations had on the quality of life for individuals with dementia. Their literature search was conducted in 2005, thus this current project examined research conducted after this period to avoid duplication.

The following databases were searched (AMED, Cinahl, Cochrane Library, MEDLINE, PsycARTICLES, PsycInfo, PubMed, UK & Ireland Reference Centre) using the key words 'Dementia and Occupational Therapy'. Additional search terms added included 'wellbeing', 'well-being' 'wellbeing', 'community', 'qualitative research' or 'qualitative studies'.

The search initially yielded 1958 papers. After completing a screening of their abstracts this resulted in 20 articles that were further analysed using the McMaster Tool for Critical Appraisal (*Law et al* 1998) with their inclusion selected on the criteria as outlined in table one.

Table One: Outline for criteria of papers analysed

<b><i>Inclusion Criteria</i></b>	<b><i>Exclusion Criteria</i></b>
Diagnosis of dementia (mild to moderate)	Individuals with severe dementia or memory impairment only
Occupational Therapy Interventions	Medical or other non-pharmacological (e.g. physical therapy) interventions
Individuals living in their own home in the community	Individuals living in nursing homes or residential care centres
Articles printed in English language	No outcome measure for quality of life or wellbeing

### *Methodological Quality Assessment*

The tools used for critically appraising literature; analyse, critique and evaluate the research to establish strong scientific evidence for treatment and interventions with the ultimate goal to bring significant improvements in care standards (Simera *et al* 2010). In addition they have a critical role in limiting biases (MacDermid and Law 2008). The McMaster tool for critical appraisal has proven beneficial in the evaluation of treatment effectiveness for occupational therapy (MacDermid and Law 2008). The McMaster Tool consists of key components (purpose, literature, design, sample, outcomes, intervention and results) and considerations (biases and clinical implication) to guide the researcher in analytically evaluating the literature (Law *et al* 1998).

### *Ethical Consideration*

Over the past number of decades, ethical issues have increased regarding research into dementia studies (Baldwin *et al* 2003). Hughes *et al* (2002) argue that health professionals have a responsibility to be sensitive and acknowledge the ethical issues when working with individuals who have dementia. Research with human participants should have informed consent; whereby individuals have been provided with information regarding the study purpose; informed their participation is voluntary and they are permitted to leave at any stage (Workman and Kielhofner 2006). Ethical consideration must take top priority in the planning of any research design (Crombie 1996; Griffiths 2009). As this project is a review of the literature and participants are not required; ethical approval was not required. However, this project will examine the effects of previous research trials and studies; therefore, it is imperative that their ethical standards are evaluated. Studies found in this research were screened for ethical procedures; although it may not be appropriate to exclude research that has not disclosed ethics or in studies where queries of ethical standards have arisen, caution was taken interpreting such data. There may be significant reasons for ethical procedures not to be disclosed or even in fact not obtained.

This project required an analytical investigation and critique of the literature, therefore it was essential that the appraisal of research was ethical and respectful (The Research Ethics Guidebook 2014).

### *Reflexivity*

Although it can be a difficult time for individuals and families and at times challenging; working with this diverse group can be a positive and rewarding experience. 'Reflexivity is a challenge to conventional ideals of science which favour professional distance and objectivity over engagement and subjectivity' (Finlay and Gough 2003, p.1). Engaging in a reflexive process enables the author to unravel ideologies and political agendas that may be concealed in their research writing (Finlay 2003). For the duration of this project, a diary was kept which provided a 'chronological record of both sequence of events and development thinking' and offered beneficial further analysis of thoughts and ideas (Ballinger 2003, p.70).

## **Findings**

Following a literature search, 20 studies were further analysed regarding their role in dementia care for individuals living in the community. Details of the studies are outlined in Appendix One. The studies were further themed under the following headings: Assistive Technology/Equipment, Caregiver, Environment and Literature Review Articles. This research sought to identify what influence occupational therapy has on the quality of life and wellbeing for individuals with dementia. Of the twenty studies, only three were found to have measured the influence of occupational therapy on quality of life or wellbeing (Appendix Two).

### *Assistive Technology/Equipment*

A study by Starkhammer and Nygård (2008) demonstrated the importance of working directly with clients when prescribing assistive technology. In this study, individuals with cognitive impairments had oven timer devices installed to reduce the risks associated with stove cookers. A number of concerns were raised including installation process and learning to operate the device with no definitive benefit concluded. Cahill et al (2007) investigating Irish people with dementia and their experiences with assistive technology reported similar findings. Simple devices such as the 'automatic day and night calendar' and 'picture button telephone' were reported to have positive benefits for enabling independence and providing reassurance for the client as well as for the caregiver. However, the more complex equipment such as the 'item locator' appeared to cause more difficulties. These studies raise concerns regarding the effectiveness of such interventions on wellbeing, i.e. positivity, feeling supported and being in control (NHS Scotland 2006).

Furthermore, a study by Nygård and Starkhammer (2007) demonstrated the importance of assistive devices to enable occupational engagement. Although they also highlighted that for many older adults, technology is a new phenomenon and therapists should be aware that individuals may require additional and follow-up assistance during the initial stages. These studies, however, did not examine what influence assistive technology has on the individual's and/or the caregiver's wellbeing and quality of life. In addition the research carried out was qualitative and although provides a great insight into the experiences of individuals with dementia and assistive technology, the findings cannot be generalised.

## Caregiver

A review of occupational therapy with caregivers for individuals of dementia in the U.K. reported significantly low literature findings and poor methodological quality in research carried out (Hall and Skelton 2012).

Research conducted by Gitlin *et al* (2007 and 2010) focused primarily on the perceived burden of the caregiver. Although they examined reducing the behaviours associated with individuals who have dementia, including environment modifications and education; they did not specifically address the individual with dementia and their occupational goals. Their research has illustrated the positive benefits for caregivers when an individual with dementia is in receipt of occupational therapy services; however, without examining the direct effects on the individual, aside from behaviour issues, it is difficult to ascertain the benefits.

In contrast, Lam *et al* (2010) concluded that caregiver burden was not reduced following their study investigating the case management model. For this intervention, an occupational therapist is assigned case manager; therefore, they are responsible to arrange home visits and follow-up communications. Home visits included assessment of occupations for the individual with dementia and advice for the caregiver around communications, safety in the home and management of behaviours. Caregivers were also given training to facilitate at home cognitive stimulation techniques (e.g. engaging in household tasks, reading the paper together). Both studies had interventions focusing on caregiver education and support; however, their findings were in disagreement.

Other researchers who have examined the caregiver role have included a comprehensive study by Graff *et al* (2006, 2007a/b) and Voigt-Radloff *et al* (2009 and 2011). Both studies examined the influence of occupational therapy on a number of factors including caregiver burden, quality of life for individuals with dementia and their caregivers, cost-effectiveness of interventions and comparing one intervention session to the COTiD program of ten sessions. Research based on the COTiD program has concluded conflicting findings. Graff and colleagues (2006 and 2007a/b) report positive benefits using the program including improvements in individual and caregiver quality of life, reduced care costs, increased function levels for the individual and an increase in competency levels for the caregiver. However Voigt-Radloff *et al* (2009 and 2011) concluded no improvements in quality of life following the COTiD program and reported that one session was sufficient to see functional levels maintained. Although the authors did state this may reflect the cohort who had lower assistance needs than previous research using this program.



## *Environment*

In a comparative study of day care centres in the Netherlands, deBruin *et al* (2011) concluded no significant difference in functional abilities comparing individuals who attended green care farms with those attending regular day care facilities. Green care farms are day facilities that provide opportunities for clients to avail of care services as well as engage in leisure, recreational, agriculture and outdoor activities. They offered a number of explanations for their findings, including frequency and duration of activities, the low participant numbers the method for gathering information which suggest further research is required to investigate the possible functional benefits for these individuals attending care centres. In addition it would also be imperative to establish the wellbeing benefits for individuals considering the significant difference of physical environment and the potential this could offer individuals. It was interesting to note that the outcome measures obtained were from caregiver observations as opposed to the individual with dementia, whom they were assessing.

Gitlin *et al* (2005) examined the caregiver in the home environment and reported positive benefits for caregiver education and skills training. However, they also state that it would be important to follow up on these programs with caregivers to provide further support and training. Given the progressive nature of dementia it would appear appropriate to provide further training that assists with declining capabilities. Although this study addressed the difficulties and occupational issues of the individual with dementia the research does not include direct measurements.

These findings however are isolated to the physical environment. There was limited research investigating the influence of the social environment on individuals with dementia. A study by Hampson (2009) explored the social environment for individuals with dementia and concluded positive effects following an occupational therapy group intervention. However, poor methodological quality with no standardised assessment or outcome measures used and the small sample size limits the findings. The influence of occupational therapy groups for individuals with dementia requires future research.

The literature search also yielded research by Callahan *et al* (2012) investigating primary care occupational therapy and the influence on functional decline for individuals with Alzheimer's disease. This study has not been completed, although the outcomes may have significant impact on future guidelines for occupational therapy in dementia care. This study conducted home visits over a two-year period consisting of up to 24, 90-minute sessions that focused on meaningful activities, as well as support and education for the individual and their caregiver.

## *Review Articles*

There have been a number of literature reviews produced in recent years (Letts *et al*/ 2011; Padilla 2011a/b) investigating occupational therapy in dementia care. However they have included large numbers of studies conducted in residential facilities limiting the findings for individuals in the community.

This literature search has found that few studies have actually sought to investigate the influence of occupational therapy with individuals who have Dementia. Although the studies focused on aspects of the individual's occupations, few looked directly at how their occupational performance and low occupational engagement may be influencing their quality of life and thus wellbeing.

## **Discussion**

This research sought to identify what influence occupational therapy has on the quality of life and wellbeing for individuals with dementia. The findings illustrated current intervention practices for occupational therapists working in dementia care. The discussion will explore these interventions and the influence on quality of life and wellbeing as well as considering the impact this evidence may have on dementia care services.

The findings have illustrated mixed effects and reinforced the acknowledgement that there is limited evidence of occupational therapy in dementia care (Perrin *et al* 2008). Indeed, it appears among the literature that few occupational therapy studies investigating dementia care have actually examined the influence on quality of life as a primary measure to their research. Critically, of the studies examined in this project only one specifically addressed the issue as their primary outcome as the sole purpose of their paper (Graff *et al* 2007b) compared to those who measured quality of life (Voigt-Radloff *et al* 2011) and wellbeing (Lam *et al* 2010) as secondary outcomes to their main research objectives. Interestingly, research by Graff *et al* (2007) appears to have been part of a large study investigating individuals with dementia and the influence of occupational therapy, these included a focus on the caregiver (Graff *et al* 2006) and the cost-effectiveness of dementia care (Graff *et al* 2007a).

Based on the findings in this research project, it could be argued that quality of life and wellbeing are not the primary investigation or objective for occupational therapy research in dementia care. However, the aim of occupational therapy is to enable an individual engage in their occupations thus promoting their health and wellbeing (Townsend and Polatajko 2007; Wilcock 2006), therefore the question must be asked as to why this is not always included as an outcome measure in research.

Research conducted by Mountain *et al* (2008) highlights the imperative need for individuals to engage in occupations in the maintenance of wellbeing and for improvements in quality of life. Given that this study focused on individuals in the older adult population, it is interesting that more precedence is not given to wellbeing and quality of life measures when research is carried out relating to older adults and occupational therapy, even those with cognitive impairments or diagnoses such as dementia. Clark *et al* (1997) emphasised the impact occupational engagement has on healthcare; improvements in health, wellbeing and quality of life saw reductions in hospital visits and medical interventions. This generates the need for further investigations as to the low numbers of research exploring quality of life for individuals with dementia following occupational therapy interventions. An increase in evidence could be the ignition for the provision of services in dementia care that has the potential to provide long-term benefits such as reducing pressures on acute and primary care services.

Graff *et al* (2007b) concluded that occupational therapy interventions improved quality of life. This study was conducted using the COTiD program. It focuses on both the individual with dementia and the caregiver, acknowledging the influence each has on the other's health related outcomes and incorporates interventions such as: compensatory strategies and environmental adaptations as well as caregiver and client education. Comparatively, Voigt-Radloff *et al* (2011) using the COTiD program to compare to one session, concluded this to be sufficient for the maintenance of functional levels in individuals with Alzheimer's disease, however not significant in influencing quality of life. Similar findings were reported by Lam *et al* (2010) stating no influence on wellbeing following occupational therapy using a case management model. The interventions in this study were also with the caregiver including advice for safety and behavior management as well as cognitive stimulation training. It is of interest to note that this study conducted their study over four months, this did not always entail face to face contact in contrast to Graff *et al* (2007b) where the intervention period was limited to just five weeks with ten one hour home visit sessions. Graff *et al* (2007b) concentrated on interventions completed during a short period of five weeks with follow-up after three months. This could suggest that continuous case involvement over a four month period would possibly provide positive outcomes, however this was unfounded (Lam *et al* 2010).

These findings highlight the continuous change of needs for individuals with Dementia and perhaps a more long-term intervention plan is required with regular occupational therapy input, for example, a two-year process with regular home visits (Callahan *et al* 2012). Unfortunately, this study is still ongoing and no conclusions have been established. This research could have significant implications for intervention planning. Interventions were carried out over a twenty-four month period with 90-minute sessions occurring once a month. This possibly enables therapists to thoroughly evaluate occupational performance.

Gitlin *et al* (2005) highlighted that interventions are rarely assessed for their sustainability, and reported interventions with a short life span have short-term positive influences. Further research would benefit to establish if these short-term influences are valuable and therefore purposeful in dementia care. However, longevity and sustainability should be considered for intervention planning, given that many individuals with dementia can live between 8-20 years following diagnoses (O'Connor 2011). The evaluation of outcomes varied across the studies ranging from 12-weeks (Graff *et al* 2006 and 2007a/b) up to two years (Callahan *et al* 2012).

Similar differences were noted regarding the level of training therapists had working in dementia care services with research by Graff *et al* (2006 and 2007a/b) involving senior occupational therapists with a minimum of 80hrs training. Lam *et al* (2010) stated case managers were trained occupational therapists, although specific details were not disclosed. Interventions carried out by therapists for Voigt-Radloff *et al* (2011) received training (16hrs) from a member of the research team prior to the commencement of the study. It could be suggested that this lack of familiarity with the COTiD program limited the possibilities for improvements. However, there appears to be a growing number of therapists specializing in dementia care. Perhaps policies and procedures need to examine providing further training for therapists (e.g. developing communication strategies) that may facilitate building rapport and engaging individuals in therapy. Although at times the illness can be difficult with many challenges, there are a number of positive benefits and rewarding experiences when working in dementia care, such as utilising memories and previous interests to engage individuals in occupations.

According to Wilcock (2006), all individuals are occupational beings with occupational needs and goals and research has highlighted the importance of occupations for individuals with dementia (Burton 2003; Egan *et al* 2006; Lee *et al* 2006). However, this project has found that much of the research focuses on the caregiver role as opposed to engaging the individual with dementia in occupations. Perrin *et al* (2008) state that dementia care should include both the individual with dementia and the caregiver where possible. The term person-centred care in dementia has been developed to ensure the individual is not forgotten; their unique qualities and traits, the relationships they have with others and importantly their life experiences (Epp 2003). It would therefore appear imperative that the caregiver is included in intervention assessment and planning but that the focus should not be on their role only but to ensure occupational balance for both caregiver and importantly the individual with dementia.

Valuable information has been obtained from recent studies investigating dementia care and occupational therapy (Gitlin *et al* 2007 and 2010; Graff *et al* 2006 and 2007a/b; Voigt-Radloff *et al* 2009 and 2011), however much of this research was conducted with a core sample of participants. It would be important to see this research repeated with participants from varied cultures and countries to ascertain the specific influence of occupational therapy and to establish how transferrable these studies are to improve the lives of those effected by dementia.

Although given that Voigt-Radloff *et al* (2009 and 2011) investigated transferring protocols from the Netherlands to examine its effectiveness in Germany for individuals with dementia it suggests that there is a trend towards applying new strategies. In addition to this study there was no improvements in quality of life in comparison to the similar intervention protocol carried out by Graff *et al* (2006 and 2007a/b), suggestive that perhaps the training of therapists played a role in the implementation of the interventions,

which would be critical if attempting to transfer application of methods to other settings in a variety of cultures and countries. This also highlights the imperative need to provide individuals with training and skills to work in dementia care.

Current occupational therapy interventions for dementia care included home visits that provided caregiver support and education (Graff *et al* 2006 and 2007a/b; Lam *et al* 2010; Voigt-Radloff *et al* 2009 and 2007), compensatory techniques and adaptations (Graff *et al* 2006 and 2007a/b) assistive technology (Cahill *et al* 2007; Nygård and Starkhammer 2007; Starkhammer and Nygård 2008) as well as interventions which address behaviour problems (Gitlin *et al* 2007; 2009; 2010). However, despite the research, little investigations have demonstrated what influence occupational therapy has on quality of life and wellbeing. The rise in dementia diagnoses (WHO 2012) and the effect on functional abilities (Alzheimer Association 2013) highlights the essential need for services in dementia care to manage and monitor the decline. There is an essential need for robust and rigorous evidence demonstrating the benefits of occupational therapy for individuals with dementia that could possibly create education and training opportunities for health professionals and in addition open up service provisions through evidence-based practice highlighting the complex needs of individuals with dementia.

## **Conclusion**

This project examined the literature in an attempt to establish how occupational therapy interventions influence quality of life for individuals with mild to moderate dementia living in the community. Occupational therapy in dementia care is a relatively new area (Perrin *et al* 2008) however; there has been substantial growth over the last fifteen years in research for occupational therapy and dementia. The findings in this project highlight the need for further research investigating quality of life and wellbeing for individuals with dementia following occupational therapy interventions. Although occupational therapy is growing in the dementia care setting, with the research demonstrating that most of the care in the community is conducted directly in the home environment where adaptive techniques, compensatory strategies and assistive technology is utilised. However, there appears to be primarily though not exclusively many interventions directed at education and support for the caregiver.

### *Limitations of this Study*

Although a comprehensive review of the literature was conducted this was not a critically adapted review of the literature. Data extraction was conducted independently as this was a small research project. With only one individual extracting information, this increases the possibility of some data being unintentionally misinterpreted, as any uncertainties were resolved independently. However, this was reduced through a reflective diary and regular discussions in supervision.

### *Implications for Practice*

This project has highlighted the imperative need for occupational therapists practicing in dementia care to maintain the integrity of the profession remaining person-centred and taking a holistic approach, considering the wider impact for the individual and their caregiver. The studies found in this research, reported the Dementia Quality of Life Instrument to be an effective measurement tool. It is important in practice that therapists take direct evidence and measurement from the individual as well as collateral from caregivers to enable positive therapeutic benefits.

### *Implications for Research*

The findings of this project have indicated the crucial need for robust investigations into the wellbeing and quality of life for individuals with dementia following occupational therapy interventions. In addition, there is an urgent need for research to explore what influence therapy has for individuals with dementia and their caregivers in the provision of services. It is also imperative that qualitative research is continued to provide an insight into the lived experience of individuals with dementia and the shared experience that occurs between individuals and their caregivers.

### *Implications for Education*

This project has emphasised the complex needs for individuals with dementia that include cognitive and functional decline highlighting the vital role occupational therapy can play. Thus, it is necessary for therapists to be adequately prepared to work in this setting. Education curriculums should focus on including communication skills and information pertaining to the trajectory of dementia to facilitate a greater understanding for the effect on occupational engagement. For graduated therapists there is a need to have courses that would provide greater understanding for person-centred care.

Current evidence for occupational therapy in dementia care services is indicative that the priority is focused on caregiver burden and addressing behavioural issues as opposed to the relationship occupations have in influencing wellbeing and quality of life for the individual with dementia. There is an essential need for therapists to be aware of the complexities dementia has on the individual and their occupations not forgetting the critical role of the caregiver in the facilitation of occupational engagement.



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## **Appendix One**

Outline of articles that were critically appraised for possible inclusion in this study.

	<b>Author (year)</b>	<b>Study Design</b>	<b>Sample Size</b>	<b>Ethical Considerations</b>	<b>Intervention</b>	<b>Findings</b>
1	Cahill et al. (2007)	Exploratory Descriptive Mixed Methods Approach	N = 34	Ethical approval granted. Informed consent verbally and written obtained from caregiver and care receiver.	Participants were given a piece of assistive technology to trial. Questionnaire was taken at baseline and follow-up. As well as interviews.	Mixed response for individuals and caregivers regarding the benefits of assistive devices. No quality of life measure.
2	Callahan et al. (2012)	Randomised Control Trial	N = 180	Approved by review board. Written information. Informed consent from client and caregiver.	Occupational therapy interventions with client and caregiver of twenty four sessions during a two-year period.	On-going research, no findings have been concluded.
3	deBruin et al. (2012)	Observational Cohort Study	N = 88	Informed consent from caregiver.	Individual with Dementia attending day care facilities were assessed to compare facilities. Primary caregivers were interviewed at beginning, 6 and 12 months.	Reported that green care farms were not effective in maintaining functional performance or reducing the decline of people with Dementia in comparison to those attending regular day care facilities. No quality of life measure.
4	Graff et al. (2006)	Single-Blind Randomised Control Trial	N = 135	Approved by the medical ethics committee. Written and verbal information provided. Informed consent obtained.	Ten one hour occupational therapy sessions per week for five weeks. Measurements taken at baseline, six weeks and 12 weeks.	Daily functions were improved for individuals with Dementia. Caregiver burden reduced. Effects maintained at 12 weeks. Part of large study which also investigated quality of life.
5	Graff et al. (2007a)	Single-Blind Randomised Control Trial	N = 135	Approved by the medical ethics committee. Written and verbal information provided. Informed consent obtained.	Ten one hour occupational therapy sessions per week for five weeks. Measurements taken at baseline, six weeks and 12 weeks.	Reduction in doctor and hospital visits. Demonstrated the cost-effectiveness of at home therapy services. Part of large study which also investigated quality of life.

6	Gitlin et al. (2005)	Randomised Two Group Design	N = 127	Caregiver consent obtained.	Occupational therapy intervention based on the Home Environmental Skill-Building Program. Five 90-minute home visits and one telephone over a six month period with maintenances being one home visit and three brief phone calls in the following six months. Measurements taken at baseline, 6 and 12 months.	Caregivers reported improved skills and a decrease in assistance needs. Reports of reduced instances of behaviour problems. Caregiver affect improved. Individual with Dementia not measured for wellbeing or quality of life.
7	Gitlin et al. (2007)	Randomised Two Group Trial	N = 272	Caregiver consent obtained.	Caregivers receive up to 13 contacts form occupational therapy or nurse interventionists. Measurements taken at baseline, 4 and 6 months.	Outlines the methodological procedure to assess home-based environment interventions in addressing behaviour difficulties for individuals with Dementia. Findings published in later paper.
8	Gitlin et al. (2009)	Randomised Two Group Trial	N - 60	Not Mentioned.	Tailored Activity Program: up to eight sessions of six home visits and two brief telephone calls delivered by an occupational therapist over four months.	Observations were noted of increased participation levels and pleasure for the individuals with Dementia. Caregivers reported gaining more control, being less distraught regarding behaviour and improved skills. No quality of life measure.
9	Gitlin et al. (2010)	Randomised Two Group Trial	N = 272	Written informed consent and proxy patient consent obtained.	16-week phase of up to nine occupational therapy sessions and two nursing sessions (home visit and phone call), then maintenance phase for eight weeks with three brief occupational therapy contacts. measurements taken at base, 16 weeks and 24 weeks.	Reported improvements in caregiver wellbeing and skills. Caregivers reported an improvement in targeted behaviour. Individual with Dementia not measured for wellbeing or quality of life.

10	Hall and Skelton (2012)	Literature Review	N = 17	Not Applicable	Examined the literature for occupational therapy in supporting caregivers for individuals with Dementia.	Many studies have poor mythological quality. Emphasised the need for more robust research.
11	Hampson (2009)	Qualitative Survey	N = 14	Not Mentioned	Limited information available, participants attended gender specific groups with their caregivers every second week	Positive benefits were reported by participants of the group and their caregivers. No quality of life measure.
12	Letts et al. (2011)	Literature Review	N = 26 articles	Not Applicable	Evidence based review to establish what interventions focused on modifying or maintaining ADLS have on quality of life, health and wellness as well as client and caregiver satisfaction for individuals with Alzheimer's Disease and other Dementias.	There is limited evidence for therapy interventions effects on individuals with Dementia.
13	Nygård and Starkhammar (2007)	Qualitative Ethnographic Design	N = 8	Not Mentioned	Interviews and observations were taken.	Highlighted the difficulties which can arise when implementing interventions with technology. No quality of life measure.
14	Padilla et al (2011b)	Literature Review	N = 33 reports	Not Applicable	Systematic review to examine what effect environment based interventions have on behaviour and performance in individuals with Dementia.	Interventions such as ambient music, aromatherapy and Snozelen® have modest effects on reduced agitation although more research required.
15	Padilla et al (2011b)	Literature Review	N = 10 articles	Not Applicable	Systematic review to examine what effect adapting the activity demands in the care of individuals with Dementia	Highlight the need for individualised programs, utilising cues to assist with task completions, importance of compensatory strategies and caregiver education.
16	Starkhammar and Nygård (2008)	Qualitative Grounded Theory	N = 14	Letter and phone call regarding the study to caregiver. Information given in writing and verbally Approved by the ethical committee.	Participants who applied and were certified by an occupational therapist or physician had a stove timer installed. Interviews and observations took place.	Technology can be beneficial but also can create challenges and difficulties. No quality of life measure.

17	Voigt-Radloff et al. (2009)	e-Blind Randomised Control Trial	Singl	N = 140	Written consent obtained from client and caregiver.	Ten one hour occupational therapy sessions per week for five weeks. Measurements taken at baseline, six, sixteen and twenty six weeks. I comparison to one occupational therapy session only following an initial home visit	No results provided, published in a later paper. This outlined methodological procedure for research.
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## **Appendix Two**

Outline of articles with quality of life or wellbeing outcome measures.

	<b>Author (year)</b>	<b>Study Design</b>	<b>Sample Size</b>	<b>Ethical Considerations</b>	<b>Intervention</b>	<b>Findings</b>
<b>1</b>	Graff et al. (2007b)	Single-Blind Randomised Control Trial	N = 135	Approved by the medical ethics committee. Written and verbal information provided to both client and caregiver. Informed consent obtained.	Ten one hour occupational therapy sessions per week for five weeks. Measurements taken at baseline, six weeks and 12 weeks.	Individuals with Dementia and their caregivers had improved quality of life scores.
<b>2</b>	Lam et al. (2010)	Randomised Control Trial	N = 102	Written consent obtained from client and caregiver Approved by clinical research ethics committee in 2003.	Case Management: participants and their caregiver assigned a case manager (trained occupational therapist). Interventions took place over four months, this included home visits and telephone communications. Specific details were not available.	There were no changes in wellbeing for the individual with Dementia and no significant effects in reducing caregiver burden.
<b>3</b>	Voigt-Radloff et al. (2011)	Single-Blind Randomised Control Trial	N = 141	Written consent obtained from client and caregiver.	Ten one hour occupational therapy sessions per week for five weeks. Measurements taken at baseline, six, sixteen and twenty six weeks. I comparison to one occupational therapy session only following an initial home visit.	Previously published paper based on same study. Ten sessions were not shown to be anymore clinically effective than one session. No improvements in quality of life for individuals with Dementia.