

Promoting Family Involvement in Residential Dementia Care: An Education Intervention

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**PROMOTING FAMILY INVOLVEMENT
IN RESIDENTIAL DEMENTIA CARE:
AN EDUCATION INTERVENTION**

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Synopsis

There has been very little empirical research in Australia that examines the role of the family caregiver of the person with dementia in residential care. Nevertheless, both in Australia and overseas, researchers and clinicians recognise that there are benefits for staff, families and their relative with dementia from increased family accessibility, involvement and engagement as clients in care.

Client partnerships are defined as dynamic, therapeutic relationships with health professionals that require articulation of common care goals, the exchange of knowledge and clarification of care roles. In the later stages of the dementia syndrome as the person with dementia experiences profound, deteriorating cognitive effects, the focus inevitably shifts to family caregivers to fulfil the surrogate role in providing information about their relatives' individual care needs.

The aim of this thesis is to explore family involvement as partners with staff in the care of their relative with dementia in residential care. This was achieved by implementing and evaluating a family-staff partnership model of care based on negotiation of therapeutic activities for the person with dementia.

The study is a partial replication of an intervention conducted in United States of America (US) with successful care outcomes. The Family Involvement in Care (FIC) education intervention and partnership model has evolved from research over the period of two decades, led by Meridean Maas. Her research demonstrated that, through education and contractual partnership, caregiving arrangements between family and staff not only improved care for the person with dementia, but also resulted in more harmonious and productive partnerships which benefit all.

The mixed method sequential design study utilised in this thesis consisted of a pre-intervention phase (Phase 1) and a post-intervention phase (Phase 2). During Phase 1 a purposive sample of ten family participants derived from the larger quantitative sample were interviewed during the month prior to the intervention. The aim of the

interviews was to explore family caregiver experiences with particular focus on (1) caregiving of their relative prior to admission to residential care, (2) feelings about admission and placement in care, (3) relationships with staff and (4) evaluation of care in the residential facility. Quantitative baseline data collection (knowledge, stress and satisfaction measures) from family (n = 57) and staff (n = 58) caregivers also occurred in Phase 1. Phase 2 utilised a controlled trial design to examine beneficial outcomes for family (n = 30) and staff (n = 31) caregivers as a result of the intervention, and to compare with family (n = 27) and staff (n = 31) caregivers who were subject to the placebo intervention. Phase 2 also consisted of interviews with the Phase 1 purposive sample of ten family participants one month following completion of the intervention. The aim of these individual interviews was to ascertain family caregivers' views of the intervention, with particular focus on their relationship with staff and their evaluation of care.

The pre-intervention qualitative findings emphasised the increasing isolation and burden of care felt by families prior to admission, which often was compounded by their grief, lack of orientation to the residential care facility and lack of knowledge about dementia. As families searched for a sense of meaning and connection with staff they wanted to know more about dementia, and in particular that 'the person' with dementia was cared for and understood by staff caregivers. In spite of placement of their relative into residential care they did not relinquish their caregiving role.

The quantitative family caregiver findings in this study identified that the major benefit from the FIC intervention for family caregivers was an improvement in knowledge about care of the person with dementia. There were no significant differences in stress levels for family caregivers following the intervention at either the control or intervention site. However, compared to the control site, family caregivers did report increased stress due to conflict with staff at the intervention site. Accordingly family caregivers at the intervention site became increasingly dissatisfied with staff consideration of their relative, physical care, activities and management effectiveness.

Similarly for staff caregivers, the quantitative findings revealed positive improvements in knowledge about dementia care. However, there was a significant

increase in staff caregiver stress at the intervention site in response to perceived inappropriate behaviour from residents with dementia. There was also a significant increase in stress levels at the intervention site, compared to the control site when promoting increased family involvement in care. The increased stress appeared to be directly related to the added burden of negotiating with family caregivers in a resource constrained environment, with minimal leadership and support from residential facility management.

At the post-intervention interviews family caregivers identified two obstacles to family involvement: loss of their allocated staff member due to structural changes, and environmental changes for their relative during the nine month period of the study. Family caregivers at the intervention site described the benefit of their partnership with staff as being an improvement in their relative's well-being as a direct consequence of their increased involvement. They acknowledged the benefit of family involvement in care of people with dementia and agreed the success of the family-staff partnership relied on whether it was promoted as part of standard care and supported by management.

In Australia, promoting family involvement in care with staff through the development of meaningful partnerships remains an under-explored area in aged care generally. This research is distinctive in that it tests the effects of a best practice partnership model of care in an Australian residential care setting. The findings from this study not only provide the impetus for further exploration of partnership models of care, but also contribute to the development of education and training of aged care clinical nurses, improved knowledge of dementia care and improved quality of care.

Publications and Conference Presentations

Refereed Publications

Bramble, M., Moyle, W., McAllister, M. (in press). Seeking Connection: Family Care Experiences Following Long-Term Dementia Care Placement. *Journal of Clinical Nursing* (Accepted January 2009).

Conference Presentations

Bramble, M., Moyle, W., Shum, D., McAllister, M. “The Family Involvement in Care (FIC) Study: A snapshot of partnership outcomes for family and staff caregivers in residential dementia care”, poster presented at the Dementia Collaborative Research Centres (DCRC): National Dementia Research Forum: Translating Research into Practice - September 2008.

Bramble, M., Moyle, W., Shum, D., McAllister, M. “Effects of the Family Involvement in Care (FIC) Intervention on caregivers of persons with dementia in residential care”, poster presented at Research Centre for Clinical and Community Practice Innovation (RCCPI), Griffith University – Asia-Pacific Research Symposium - July 2008.

Bramble, M., Moyle, W., Shum, D., McAllister, M. “Family Involvement in Care (FIC) Study: An education intervention to promote family involvement in residential care”, poster presented at Asia-Pacific Regional Conference of Alzheimer’s Disease International - June 2008.

Bramble, M., Moyle, W., McAllister, M. “Seeking Connection: Family experiences of the care of the person with dementia following residential placement”, poster presented at Dementia Collaborative Research Centres: National Dementia Research Forum: Translating Research into Practice – September 2007.

Bramble, M., Moyle, W., Shum, D., McAllister, M. “The Family Involvement in Care (FIC) Study: A New Generation Partnership Model of Dementia Care”, paper presented at the Alzheimer’s Australia Conference: A Journey of Passion and Purpose - May 2007

Statement of Originality

This work has not previously been submitted for a degree or diploma in a university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

Marguerite Dorothy Bramble

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Glossary of Key Terms and Abbreviations

Following is a list of terms and abbreviations used throughout the thesis

Term	Definition
Aged Care Assessment Team (ACAT)	Team of health professionals who conduct assessments of older people to assist them gain access to the types of services appropriate to their needs.
Aged Care Funding Instrument (ACFI)	A nationally consistent instrument, which assesses a residential care recipient's needs based on level of dependency (replaces RCS).
Burden of disease	The total significance of disease for society beyond the immediate cost of treatment. It is measured in years of life lost to ill health as the difference between total life expectancy and disability-adjusted life expectancy.
Caregiver burden	The extent to which family caregivers perceive their emotional or physical health, social life and financial status has suffered as a result of caring for their relative.
Captivity	Restrictions imposed on family caregivers by the obligations to provide care.
Community Aged Care Packages (CACPs)	Provides a planned and managed package of care, tailored to individual needs, such as bathing, shopping and housework – requires ACAT assessment.
Community Care	Provision of care and support for people who want to stay independent and living at home for as long as possible. Includes HACC services, CACP and respite services.
Dementia	Not a disease itself, but group of symptoms that characterise diseases and conditions; it is

	commonly defined as a decline in intellectual functioning that is severe enough to interfere with the ability to perform routine activities.
Disability-adjusted life years	The number of healthy years of life lost due to premature death and disability.
Dominion	Staff caregiver attitudes of control of care vis-à-vis family caregivers.
Extended Aged Care at Home Dementia Packages (EACH D)	Individually planned and coordinated packages of care, tailored to provide high level care needs at home because of behavioural problems associated with dementia – requires ACAT assessment.
EEN	Endorsed Enrolled Nurse
Exclusion	Staff caregiver resistance to involvement in care of the person with dementia from family caregivers.
Family caregiver	A family member who assumes responsibility for caregiving for the person with dementia.
Family Involvement in Care (FIC) Protocol	Education intervention and partnership model of care for family caregivers of residents with dementia.
Formal carer	A staff caregiver employed in the health and community sector (formal care).
Government transfer payments	Government payments, such as grants or social security, which are not payments in return for productive services.
High care	This level of care required is broadly equivalent to the ‘nursing home’ level of care provided under aged care arrangements previous to the RCS and ACFI. This level of care is for people who need almost or complete assistance with most daily living activities.
Home and Community Care	Provision of basic help at home to promote

(HACC)	independence – does not require ACAT assessment.
Informal carer	Someone, such as a family caregiver, friend or neighbour, excluding paid or volunteer carers organised by formal services, who has been identified as providing regular and sustained care and assistance to the client without payment other than possibly a pension or benefit.
Intervention	An activity or set of activities aimed at modifying a process, course of action or sequence of events, in order to change one or several of their characteristics such as performance or expected outcome.
Low care	This level of care required is broadly equivalent to the ‘hostel’ level of care provided under aged care arrangements previous to the RCS and ACFI. This level of care is for people who need some help, but do not have very complex ongoing care needs.
Partnership of Care	Therapeutic relationship between family and staff caregivers based on a cooperative role relationship in caring for the person with dementia.
PCA	Personal Care Assistant
Person-centred care	Care that aims to maintain the personhood of individuals with dementia and their caregivers.
Personhood (Kitwood)	“A standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust.” (Kitwood, 1987, p 8).
Primary family caregiver	A family member who assumes the chief

	responsibility (at least 50%) of care for the person with dementia.
RCF	Residential Care Facility.
Resident Classification Questionnaire (RCS)	A nationally consistent instrument, which assesses a care recipient's needs within 8 classification levels, ranging from low to high care, each paying a specific subsidy level (now replaced with ACFI).
RN	Registered Nurse
Respite care	Substitute care that can be arranged for planned breaks, regularly weekly breaks, short holidays or emergencies. Services specifically cater for medical or behavioural disturbances.
Role conflict	Conflict between two individuals about role performance expectations.
Role inadequacy	Difficulty in fulfilling role obligations in the time available.
Role overload	Defined as subjective feelings of frustration, tension and anxiety.
Role strain	Defined as the emotional costs of caregiving, eg feeling angry or overworked.
Role stress	Defined as the lack of benefits from caregiving, as a result of role conflict, strain and overload.
Task burden	A subjective state of emotional arousal in response to the external conditions of social stress. Measured by such feelings as stress, anxiety and frustration.
Treatment effect	A measure of the difference in outcome between intervention groups. Often referred to as the "effect size".

CHAPTER 1

BACKGROUND AND OVERVIEW

Overview of Dementia and Epidemiology

Dementia is a complex syndrome with a mixed aetiology caused by degenerative diseases of the brain. The World Health Organisation (WHO) defines dementia as:

.... a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded (WHO, F00-F99).

The onset of dementia occurs most commonly in people older than 65, and the cognitive impairment is usually accompanied or preceded by behavioural changes such as a deterioration in emotional control, or a change in general motivation or social behaviour (World Health Organisation (WHO), 2003). Because of the behavioural disorders associated with the syndrome it has been categorised by WHO under 'Mental and behavioural disorders'. Typically, the progression of the disease is slow and medicine has had little success in prevention or delay of onset, with no cure yet in sight (Bartlett, Gray, Byrne, Travers, & Lui, 2007).

The most prevalent form of dementia is Alzheimer's disease (AD), representing approximately 50% of all cases (Bartlett et al., 2007). Other major causes include vascular dementia (VaD), which accounts for approximately 20% of all cases and Lewy body dementia, representing around 15% of cases (Bartlett et al., 2007; Jacques & Jackson, 2000). It is estimated that frontotemporal dementia accounts for approximately 5% of cases and that the prevalence of dementia in Parkinson's disease is 3-4% of all cases (Aarsland, Zaccai, & Brayne, 2005). Thus the common forms of dementia account for 95% of cases, with the more rare forms of dementia subtypes, such as Creutzfeldt-Jakob dementia, HIV complex, demyelination, Huntington's

disease, alcohol related disease and dementia due to infectious and metabolic causes accounting for the remaining 5% (Bartlett et al., 2007).

Worldwide, as populations continue to age, dementia has become an issue of international public health concern and is considered to have reached epidemic proportions (Access Economics, 2006). Meta-analyses and large scale pooled analysis of global dementia prevalence provided to WHO have identified similar prevalence and incidence estimates for the developed world regions, including Australia, the United Kingdom (UK), the US and Western Europe (Ferri et al., 2005). In the Asia Pacific Region, as average life expectancy continues to rise, it is predicted that the incidence of dementia will be three to four times higher than in developed regions (Access Economics, 2006; Ferri et al., 2005). Current estimates are that China already has the highest number of people with dementia (six million), followed by Western Europe (4.9 million) and 3.4 million in the US (Bartlett et al., 2007). As a member of the Asia Pacific region there are implications for Australia to support less developed countries in meeting the challenges ahead, particularly with respect to early intervention, family caregiver education, staff training and service delivery (Access Economics, 2006).

In Australia there were approximately 175,000 people living with dementia in 2003, with the number of cases expected to rise to approximately 465,000 by 2031 (Australian Institute of Health and Welfare (AIHW), 2007a). The major emerging predisposing risk factor is age with both prevalence and incidence rising exponentially, resulting in more than doubling of the rate every five years, from approximately 1% at age 65 to 50% at about 95 years (Access Economics, 2004). There is a slightly greater prevalence in females over 75, compared to males for AD, and a greater prevalence in males of VaD (Bartlett et al., 2007). Approximately 37,000 new cases are diagnosed every year, of which 23,000 are female and 14,000 are male (AIHW, 2007). Of the three classifications of dementia severity it is estimated that 55% have mild, 30% have moderate and 15% have the severe stage of the disease (AIHW, 2007). Within the aged care system dementia care is emerging as a significant aspect of care across the spectrum of aged care service delivery.

Australia's Aged Care System

Australia's aged care system is described as mixed and is separated into informal and formal care. Informal care is mostly provided by family or friends of the person who requires care and is distinguished from the services provided by people employed in the health and community sector (Access Economics, 2005b; Hogan, 2004). The three main categories of formal care are community care, residential low care (formerly known as hostel) and residential high care (formerly nursing homes). Community care can be provided as a low care service through Community Aged Care Packages (CACPS) and Home and Community Care (HACC). Community high care services, which aim to provide care at home equivalent to high-level residential care, are provided through the Extended Aged Care at Home program (EACH) (Australian Institute of Health and Welfare (AIHW), 2007b). Residential aged care is provided either at a low care or high care level of intensity (Access Economics, 2005b). Within this system the level of care and services provided to the person with dementia depends on the type of dementia diagnosed, and their assessed level of dependency as identified by both the Aged Care Assessment Team (ACAT) and informal carers. Since 2005 a limited number (2,000 places Australia wide over three years) of EACH Dementia packages have been offered specifically to assist families in providing high care for people with dementia at home (Hales, Ross, & Ryan, 2006; Productivity Commission, 2008). Whilst it may be assumed that the service would be characterised by a high degree of contact between staff and clients, to date the success of this specialised service has not been formally evaluated (Productivity Commission, 2008).

Compared to other chronic conditions dementia now has the greatest prevalence in residential aged care services and it has been estimated that up to 80% of permanent residents probably or possibly have dementia (AIHW, 2004). Of those with dementia still residing in the community who receive community care assistance, it is estimated that 97% who remained at home required a carer, compared to 88% of recipients without dementia (AIHW, 2004). Accordingly, the economic cost of the epidemic continues to escalate with rising prevalence, and the real financial cost of dementia in Australia, already around 1% of the Gross Domestic Product (GDP), is predicted to rise to 3.3% by 2050 (Access Economics, 2006). These estimates represent about

\$33.6 billion dollars of ‘direct cost’ for residential and specialist services and \$26.8 billion for estimated costs of informal care (AIHW, 2006). These costs are calculated based on the burden of disease caused by dementia, with disability accounting for three-quarters of the disease burden, rather than premature death.

Dementia and Burden of Disease

Whilst the search continues for more effective treatment, it is clear that the impact of burden of disease will continue to increase as more people with dementia need care both from informal and formal carers in the community and residential care.

Currently, approximately 86% of permanent residents with probable dementia are already in the highest Resident Classification Questionnaire (RCS) care need categories, compared to 35% of those with possible dementia and 8% of those without dementia (AIHW, 2004). People with dementia also tend to, on average, have longer stays in residential care than those free from the condition, with relative use of bed days increasing from approximately 73% in 1998 to at least 80% in 2002 (AIHW, 2004). At current estimates the projected increase in demand for high care residential beds is from less than 100,000 in 2003 to 337,000 by 2050 (Access Economics, 2005a; Productivity Commission (PC), 2006). Thus, with the extended time of disability rather than death, dementia is now the greatest single contributor to burden of disease in the older population, and the second greatest single contributor to the cost of residential care (Anand & Hanson, 2004; AIHW, 2007a).

In the light of the increasing demands on services from the so called ‘dementia epidemic’ and the absence of a cure, scientists, health professionals and those families affected by dementia are requesting more appropriate and therapeutic means of both treatment and care to support informal and formal carers across the community and residential care settings (Access Economics, 2006). In the earlier stages of dementia such aspects of treatment and care as earlier diagnosis and family caregiver education and support are required to reduce the disease burden by slowing the progression of the disability (Access Economics, 2006; Robinson et al., 2009). Similarly, later in the dementia trajectory, as the dementia symptoms and behaviours worsen, appropriate care and therapeutic interventions are required that continue to provide relief from disease burden, particularly family caregiver burden, as they attempt to manage their

own physical, emotional and financial stress from caring (Access Economics, 2006; Bartlett et al., 2007; Tilly & Rees, 2007).

Dementia and Caregiver Burden – Informal and Formal Carers

The issue of dementia and family caregiver burden has been the focus of research for a number of years. Contemporary research is identifying more clearly the causes, extent and risk factors associated with disorders suffered by family caregivers of people with dementia in the community (Brodaty, 2007; Brodaty, Green, & Koschera, 2003; Cuijpers, 2005; Mills, Dimsdale, Ziegler, & Patterson, 2004). Such studies support the growing body of evidence that informal carers of people with dementia, particularly those who are themselves elderly and subject to physical frailty, experience a significant increase in psychological morbidity over time, whereas their counterparts of people without dementia experienced a decrease (Australian Government, 2002; AIHW, 2007a; Mason, Wilkinson, Moore, & McKinley, 2003). A number of studies highlight that there is a direct correlation between the prevalence of dementia and caregiver burden, and that the burden of care does not necessarily cease following institutionalisation (Brodaty, 2007; Brodaty, Green et al., 2003; Butcher, Holkup, Park, & et al, 2001; Gaugler, 2005a).

Caring for people with dementia is also stressful for formal carers and is cited as one of a number of factors contributing to recruitment and retention challenges for aged care organisations and leading to job dissatisfaction (Hsu, Moyle, Creedy, & Venturato, 2005). The consequent very serious workforce issues related to chronic staff shortages place more demand on those who remain employed in the aged care industry, compounded by a lack of educational opportunities and a clear career path in an increasingly complex environment (Davies, 2001; Hogan, 2004). As a consequence the mismatch between staff skills and knowledge of the needs of both the person with dementia in residential care and family caregivers, increasingly leads to role strain, role conflict and role overload, both for family and staff (Buckwalter, Maas, & Reed, 1997). With the inevitable increase of people with dementia, both in the community and admitted to residential care, there is an increasing need for research that furthers our understanding of institutional caregiver burden and its economic impact on the productivity of aged care health service delivery (Productivity Commission, 2008).

The Social and Economic Impacts of the Ageing Population

In Australia and other developed countries, the impact of the ageing population is driving fundamental economic change, with government expenditure on aged care expected to double during the next forty years (Cooper & Hagan, 1999; Productivity Commission (PC), 2006). During the implementation of the 1997 Aged Care Act, social policy reforms focussed on providing community care options as a way of achieving the most cost-effective outcomes in aged care (Access Economics, 2006; Australian National Audit Commission, 2005; Courtney & Briggs, 2004; Hogan, 2004). However there is mounting evidence to suggest that the focus on community driven aged care service delivery occurred at the expense of appropriate and sustainable management and growth in more specialist care services, including respite care (Abbey, 2006; Adams & Moyle, 2007; Davies & Nolan, 2004; Hogan, 2004; Queensland Health, 2006; Venturato, Kellett, & Windsor, 2006). Furthermore, the continuity between community care and residential care has become more fragmented, resulting in an increasing disparity between service requirements, user involvement and service provision (AIHW, 2002).

This gap is increasingly evident in delivery of dementia care services. With the dual social and economic drivers of the ageing demographic profile and the more complex epidemiology of dementia, aged care service providers recognise the need to bridge the increasing service gap by developing more therapeutic, evidence based models of care across the aged care system (AIHW, 2004; Courtney & Briggs, 2004). Whilst it is increasingly clear that more nursing resources are required to provide a higher degree of direct client care, there is very little understanding and a paucity of research in Australia that specifically attempts to address the costs of providing optimum quality care (Nepal & Ranmuthugala, 2008; Zhang, Unruh, Liu, & Wan, 2006). What is known is the large variation in service costs, ranging from low cost government transfer payments to informal carers, to the high costs associated with establishing and operating high-level residential care facilities (RCF's) (AIHW, 2004). As the need for high-level residential care in the aged care population continues to increase, economists and policy makers continue to search for ways to improve productivity in order to achieve higher rates of return for their funding inputs (Hogan, 2004;

Productivity Commission, 2008). However, it may be argued that the focus on minimising staffing ratios in order to achieve higher rates of return has been counterproductive to improving service delivery, particularly in residential dementia care (Zhang et al., 2006).

The Issue of Productivity Growth in Aged Care

Productivity growth is identified as an important means for service providers to reduce the costs of service provision and/or improve service quality (Productivity Commission, 2008). Whilst in recent years aged care providers have made some productivity improvements through restructuring the workforce and increasing the use of assistive technologies, strategies to improve productivity through regulatory reform and changes within operations seem to have been exhausted (Productivity Commission, 2008). One option is for providers to adopt innovative practices in their operations within the existing regulatory framework, with the view to removing unnecessary regulatory constraints as they become redundant, thus improving scope for service and productivity improvements (Hogan, 2004).

From a clinical perspective the most effective way to increase service scope is firstly to build knowledge through research-based practice that is appropriate, meaningful and feasible (Pearson, 2004). There is growing recognition that policy reform needs to occur in relation to current funding arrangements for aged care programs across the spectrum of residential and community care (Hogan, 2004; Knapp, 2007; Productivity Commission, 2008). Similarly, there is an increasing trend for government to invest in health research that aims to develop evidence based interventions and treatments that may not only reduce the direct costs of care and improve productivity, but also provide the basis for new models of service delivery (Pearson, 2004). Moreover, it has been argued that focussing on more effective health care and productive service delivery may deliver more action from government than the continued attention on the costs of nursing attrition (Eley, Buikstra, Plank, Hegney, & Parker, 2007).

Staffing Recruitment and Retention Issues

For the past decade or more there have been increasing difficulties attracting and retaining suitably qualified nurses to aged care (Nay & Closs, 1999). Concurrently

the impact of government policy and reform, driven by the Aged Care Act (1997), has served to further devalue professional nursing in residential aged care by deregulating staff mix requirements and staff ratios (Courtney, Abbey, & Abbey, 2004; Venturato et al., 2006). The impact on Registered Nurses (RNs) and Endorsed Enrolled Nurses (EENs) who remained was increased work stress and role conflict as expectations to be clinicians, as well as managers of unqualified staff, increased. The prevalence of dementia and associated complex chronic illness and disabilities has also escalated, culminating in huge disparities between the needs of residents and families in residential care and the availability of suitably qualified specialist nurses to provide quality care (Moyle, Skinner, Rowe, & Gork, 2003; Venturato et al., 2006). This issue is of particular concern when caring for residents with dementia, whose inappropriate behaviour places added stress on staff who are not trained sufficiently to care for them (Furaker & Nilsson, 2009; Pekkarinen et al., 2006). Studies also identify that two of the major factors contributing to job dissatisfaction are tensions within role expectations and the increasingly complex needs of residents (Koch & Tiziani, 2004).

A strong indicator of the ongoing problems of recruitment and retention in aged care facilities is the decrease in the number of RNs and EENs; 38 633 in 1995 to 34 031 in 2005, despite the increase in both the workforce and aged care places (Productivity Commission, 2008). A number of reports have highlighted the challenges of improving the attractiveness of aged care for health professionals, including improving wages, providing education and training opportunities and providing more opportunities for involvement of informal carers as a means of improving productivity (Hogan, 2004; Productivity Commission, 2008; Richardson & Martin, 2004). Hand in hand with promoting these opportunities is the need for organisations to develop a culture in which nursing staff develop leadership and teamwork skills and participation in decision making (Alzheimer's Australia, 2007; Luthans & Jensen, 2005; Sikorsda-Simmons, 2005). Indeed, nursing is in a prime position to generate empirical research based on multi-disciplinary approaches to family caregivers that may be translated to clinical practice (Algase, 2007).

Promoting Family Involvement in Care

In health care and aged care generally there is an increasing emphasis in Australia on family partnerships as a means of improving care (Bauer, 2006; Bauer & Nay, 2003; Haesler, Bauer, & Nay, 2006). Inherent in this approach is the importance of the role of RNs, firstly in health promotion through establishing therapeutic relationships and secondly promoting the potential benefits of partnerships in care to improve quality of care (Australian Nursing & Midwifery Council, 2006; Haesler et al., 2006). Because of the long-term nature of the dementia syndrome one of the major factors that separates the care of older persons with dementia from the health sector generally is the increasingly key role family caregivers play in direct service provision through the course of the disease. With the increasing prevalence of dementia as a subgroup within the aged care system, understanding the role of families and the special challenges they face becomes paramount (Stone, 2001; Tilly & Rees, 2007). The major challenge is to understand the environmental and role changes for family caregivers, driven by the care needs of the person with dementia as the syndrome advances. It is clear that lack of preparation by health professionals for these inevitable changes inevitably increases caregiver burden (Haesler et al., 2006).

A fundamental aspect of the nurse's role is to establish therapeutic relationships with clients, whether it be on a clinical level in the short-term acute environment, or a person-centred 'connected' level in long-term care (Brooker, 2007; Stein-Parbury, 2009). Both in the UK and the US there has been a flourish of work in research and practice which aims to engage people in the later stages of dementia and their families more positively with care providers and nurses through the development of person-centred approaches and partnership models of care (Brooker, 2001; Keady & Harris, 2009; Maas et al., 2004; Maas, Swanson, Buckwalter, Lenth, & Specht, 2000; Woods, Keady, Ross, & Wenger, 2008). In both countries this notion of partnership between families and staff derives from the view that families themselves are clients and a potential resource for improving quality of care of the resident with dementia (Maas, Buckwalter et al., 1994; Nolan, Davies, Brown, Keady, & Nolan, 2004).

Overseas there is increasing evidence in the community setting that Consumer-Directed Care (CDC), or client driven care, is successful in increasing family

caregiver involvement by providing them with increased autonomy and more opportunity as consumers to direct care and care choices for their relative with dementia (Howe, 2003; Tilly & Rees, 2007). Whilst it may be argued that such alternatives are currently available in Australia through the different community programs, it is also contended that the continuing dominance of government funding over the level of capacity for decision making by people with dementia and their family caregivers is preventing development of consumer-directed (and in the case of persons with dementia, caregiver-directed) care (Tilly & Rees, 2007). Such choices could be extended to the consumer by involving them in planning care for their relatives at home, thus alleviating at least some of the caregiver burden associated with making the decision to place them in residential care and reduce the increasing demand on residential services (Brodaty, Thomson, Thompson, & Fine, 2005; Tilly & Rees, 2007).

Justification for the Study

Despite some studies identifying the need for increased family involvement in residential care, in comparison to the UK and the US, Australia lags behind in both empirical research and development of a range of care choices that would be more suitable for people with dementia and their family caregivers (Bauer, 2006; Bauer & Nay, 2003; Kellett, 2007). As the person with dementia's cognitive capacity and level of engagement deteriorates it is the family caregiver who becomes the surrogate client, and their involvement in the daily therapeutic practice of nurses provides a potential resource for understanding their relative's individual care needs. The rationale for this study therefore is to examine, through empirical research, innovative ways of extending nurses' scope of practice through education and family involvement, which may then improve quality of care and productivity rather than simply aiming for profits through cost reduction (Courtney et al., 2004; Jackson, Mannix, & J, 2002; Nay, 2004; Venturato, Kellett, & Windsor, 2007).

In Australia and overseas, as the prevalence of people with dementia continues to increase, all health disciplines are challenged to find ways of addressing the increasing demand for dementia-specific services by developing more innovative and specialised models of long-term care (Hobbs & Teel, 2005; Pekkarinen et al., 2006; Robinson & Pillemer, 2007). If the epidemiological data is correct and there is a four

fold increase in the number of dementia cases between 2000 and 2050, it is imperative that research continues to find ways both to treat the underlying diseases and develop successful care interventions to improve quality of life for people with dementia and their caregivers in all care settings (Access Economics, 2003; Bartlett et al., 2007; Hogan, 2004; Productivity Commission, 2008).

The most recent research in the UK continues to emphasise the profound impacts for family caregivers associated with adjusting to their roles in the residential care environment (Woods, Keady, & Seddon, 2007). In the Australian context little is understood about the decision making processes that accompany placement in residential care. Understanding of client need also remains limited, with very little focus on care driven by client expectations and client satisfaction (Edwards, Courtney, & Spencer, 2003). Indeed, the notion of satisfaction can also be problematic if it indicates that families are satisfied because they believe there is no other option (Gaugler, Leitsch, Zarit, & Pearlin, 2000; Maas et al., 2000). There is an imperative therefore for health professionals to build best practice expertise for care provision, to increase nursing leadership and staff education through broadened scope of practice, and to develop partnership models of care as a precursor to multimedia and professional education programs tailored to dementia care (Bauer, 2006; Beauchamp, Irvine, Seeley, & Johnson, 2005; Kellett, 2007).

One of the major obstacles to developing research-based clinical practice and education programs is the latency period between translating research into practice by developing a therapeutic activity, and identifying standard measures for its outcomes (Brooker, 2001). The current empirical research in residential dementia care in Australia provides little evidence of the therapeutic benefits to families and staff of formal care relationships. An evidence-based intervention is needed to increase understanding of how therapeutic relationships with family caregivers may relieve the stress and caregiver burden of the consequences of dementia, both before, during and following placement in residential care (Gaugler, 2005b; Maas et al., 2004). In the US, the Family Involvement in Care (FIC) intervention, which has been implemented in a number of residential care facilities (RCFs), draws on the experience and observation of family caregivers of people with dementia in residential care. Driven by the theoretical frameworks of person-environment fit and role theory, the essential

premise of the intervention is that residential placement changes the status of all caregivers involved with the person with dementia. Initial research conducted in Australia has identified similar problems for family caregivers in adapting to their new role in residential care (Bauer, 2006; Moyle, Edwards, & Clinton, 2002).

The Research Project

The FIC research, led for more than two decades by Professor Meridean Maas, has provided strong evidence that, following residential placement, family caregiver involvement in care not only provides them with relief from disease burden, but also reduces role strain and care burden for staff (Maas et al., 2000). The FIC education intervention therefore provided a strong framework for understanding the roles of families and staff when developing partnerships in care.

The FIC education intervention involves family and staff in a contractual partnership based on negotiation of therapeutic activities for the person with dementia. The intervention has been trialled and implemented in the US with successful care outcomes (Maas & Buckwalter, 1990; Maas, Buckwalter, Kelley, & Stolley, 1991; Maas, Buckwalter et al., 1994; Maas et al., 2004; Maas et al., 2001; Maas et al., 2000; Maas, Swanson, Specht, & Buckwalter, 1994). This study aims to implement and evaluate the FIC family-staff partnership model of caring for people with dementia in Australian residential care settings.

Aims of the study

This study aims to provide new knowledge about the benefits of family involvement in residential dementia care by implementing and evaluating an innovative partnership model of care in an Australian residential care setting. The US studies indicate that the FIC intervention is effective in reducing family and staff caregiver stress and for improving the attitudes of staff about family members caring for persons with dementia in residential care (Maas et al., 2004; Maas et al., 2000; Pringle Specht, Park, Maas, Swanson, & Buckwalter, 2005). Whilst the FIC intervention produced beneficial outcomes in the US in their dementia-specific facilities known as Special Care Units (SCU), their funding arrangements, staffing ratios and physical environments differ from the Australian system. Furthermore, at the time of the study in the US (1997) the resident population had a formal dementia diagnosis which was

predominantly of the Alzheimer's type. Consequently, whilst this study used the concepts, longitudinal design and measurement tools developed in the FIC studies, family and staff caregiver participants were recruited from all areas of the residential care environment as well as the SCU. Furthermore family caregivers of all residents diagnosed with dementia, not just Alzheimer's disease, participated in this study. As a consequence measurement tools for residents with dementia were not included in this study.

The aim of this study therefore, as a partial replication, is to test the therapeutic effects of the intervention on family and staff caregivers in the Australian context, and to ascertain its feasibility by determining any cross-cultural differences in the findings. The question driving the study therefore becomes:

Does the FIC Model of Care, based on the theoretical models of person-environment fit and role theory, promote and improve the health of family and staff caregivers in residential dementia care?

Significance of the study

The information provided in this study contributes to dementia research by exploring and clarifying the important role of families as clients and their desire to fulfil that role. Despite growing attention in nursing and health literature to the importance of partnerships of care there remains a paucity of empirical research in Australia in nursing practice generally. This mixed method, sequential design study, which examines the success of a partnership model of care in residential dementia care, has the potential to inform evidence based practice and contribute to the training of aged care clinical nurses. It also has the potential to reduce caregiver burden by improving staff and family caregiver knowledge, reduce role conflict and improve unsatisfactory role relationships (Bauer, 2006; Hsu et al., 2005).

Currently role stress has been identified as one of the major reasons for the emotional exhaustion identified in aged care nurses (Hsu et al., 2005). Positive interactions with families has been shown to lead to improved job satisfaction (Gaugler, 2005b; Gaugler & Ewen, 2005; Robinson & Pillemer, 2007). A reduction in role conflict stressors has the potential to not only reduce staff work-related stress but also improve

knowledge and attitudes towards work and residents with dementia (Morgan, Stewart, D'Arcy, Forbes, & Lawson, 2005). Finally, the study has the potential to inform the modest evidence available on the most cost effective utilisation of scarce resources in the dementia field to achieve best practice care (Brock, 2004; Knapp, 2007). Thus the links would be made between emerging best practice, the core functions of public health practice and the business of economic discourse (Angus & Nay, 2003).

Dissertation Framework

In light of the discussion and aims presented in this Chapter, Chapter Two presents a review of relevant research associated with family involvement in care of the person with dementia in residential care. Firstly, contemporary studies examine family caregiver burden, the transition to residential care and the role of families in residential care. Secondly, the challenges of residential placement are discussed from the social and cultural perspective of the 'person' with dementia specifically in residential dementia care. Thirdly, issues are raised that currently affect nurses and care staff in the area of residential dementia care. Fourthly, an overview is given of how partnership models of care have evolved to encourage family involvement. Finally, the FIC research, its development, strengths and weaknesses are discussed, with an overview of the FIC theoretical framework and model of care. This chapter concludes by summarising the findings from the literature search and review.

Chapter Three outlines the methodological considerations of the study, its design, theoretical framework and instruments, and demonstrates that the framework and timing of the study were successfully adhered to. The mixed method, sequential design research consisted of two phases: the qualitative data, which examined family caregiver experiences pre and post the education intervention, was supported by the quantitative data and allowed for statistical analysis of its success. Analysis of pre and post quantitative data from staff also allowed for statistical analysis of the impact on them of the intervention.

The pre-intervention family member qualitative findings are presented in Chapter Four, within the following four content areas that are linked to the theories of person-environment fit and role theory: 1) caregiving prior to placement; 2) the process and

feelings for family caregivers associated with placement; 3) perceptions of the care relationships between family and staff; and 4) evaluation of care in the facility. The chapter presents the experiences of ten family members, drawn from the larger study group at both the intervention and the control sites.

Chapters Five and Six discuss the quantitative findings for both family and staff caregivers. Firstly, descriptive data in relation to demographic, caregiver and resident characteristics of the study sample are presented. Secondly the pre and post-intervention statistical analysis and findings are presented. Thirdly, a descriptive comparison of family and staff caregiver outcomes is provided to compare and contrast any cross cultural differences with the US Maas et al. study pre and post-intervention (Times 1 and 2).

Chapter Seven presents the views of family caregivers on the success of the FIC intervention. The discussion in Chapter Eight links the qualitative and quantitative findings to the theoretical framework and examines this study in the context of relevant contemporary literature. Finally, Chapter Nine makes conclusions and recommendations for research, education, practice and policy within the aged care system.

CHAPTER 2

LITERATURE REVIEW

Introduction

Chapter One provides the setting for understanding the complexities of dementia caregiving within an epidemiological, social and economic policy perspective. Australia's Aged Care System is discussed, with a brief overview of the roles of informal and formal carers, caregiver burden and the pressing issues related to staffing recruitment and retention in residential aged care. Based on the epidemiological data, issues in relation to the provision of dementia specific services are raised, with discussion on how more productive relationships between staff and family caregivers may reduce the burden of caregiving, improve the care environment and hence quality of care for the person with dementia.

This chapter closely examines the research literature pertaining to both family and staff caregivers of persons with dementia in residential care. Firstly, the experiences of family caregivers during the transition to residential placement are explored. Secondly, the challenges of residential placement are discussed from the social and cultural perspective of the 'person' with dementia in long-term residential care. Thirdly, issues are raised that currently affect nurses and care staff working in aged care generally, and particularly in the area of residential dementia care. Fourthly, a critique of contemporary research in the area of family caregiving of persons with dementia is presented, including the development of partnership models of care to encourage family involvement. Fifthly, the FIC research, its development, strengths and weaknesses are discussed. Finally, an overview of the FIC theoretical framework and model of care are presented.

Transitioning from Informal to Formal Care

It has been shown that the care needs of people with dementia, whether they are living in the community or in residential care, are greater than those who do not have the

disease (Australian Government, 2002; AIHW, 2004). Until recently the predominant focus of family caregiver research overseas has been in the community setting (Keady & Nolan, 1995; Nolan & Dellasega, 1997; Schulz & Martire, 2004; Toranatore & Grant, 2004). However, as the prevalence of dementia in residential care continues to increase, so does the need to provide specialised care for the needs of those with more advanced dementia (Port et al., 2005; Reid, Chappel, & Gish, 2007). The behaviour problems associated with the syndrome, including memory loss, confusion, loss in judgement, logic, orientation and functional abilities are primary factors for families in making the decision to seek assistance (Maas et al., 2004). In their home environment family caregivers attempt to ameliorate the changes and increasing frailty that occur as a result of the dementia but often themselves experience health problems, exacerbated by emotional and physical exhaustion (Access Economics, 2005b; Maas et al., 2004). Access to ongoing community support and information about services available is often limited, placing additional stress on the family caregiver as they struggle with the increasing demands of their relative. Consequently the family caregiver's deteriorating health may be the precursor to admission of the person with dementia to residential care (Bauer & Nay, 2003; Maas, Swanson et al., 1994).

Both in Australia and overseas, a number of contemporary studies examine the issues associated with making the decision to transition to residential care (Bauer & Nay, 2003; Buhr, Kuchibhatla, & Clipp, 2006; Davies & Nolan, 2004; Hagen, 2001; Kellett, 2000, 2006; Mitrani, Lewis, Feaster, Czaja, & et al., 2006). The longitudinal study by Buhr et al. (2006) in the US identifies more closely the multi- factorial reasons behind family caregivers' decisions to seek placement for their relative. This was achieved by collecting data from both the family caregiver and the person with dementia for twelve months before institutionalisation. The research demonstrates that the major indicators associated with the reasons for placement often are present for up to twelve months before a decision about care was made. The major reasons identified were the need for skilled care (65%), the caregivers' health (49%) and the need for professional assistance (23%). The study emphasises the importance for service providers to both recognise and acknowledge the validity of the reasons given by family caregivers, and to use them as clues to support discussion about residential care placement as they arise (Buhr et al., 2006).

Research in the UK by Davies and Nolan (2004) also focused attention on the needs of family caregivers during the time of admission of their relative with dementia to care. Data from 37 semi-structured interviews were analysed in order to better understand family perceptions of the experience of residential care placement. The findings from this study once again highlight the issue of lack of support and preparation from health professionals for the realities of nursing home care, both for family caregivers and the care recipient prior to admission. At the same time, the findings suggest that staff fail to call on families' experience and knowledge about the person with dementia both before and during residential admission. Hence the study supports the growing evidence of the significant impact staff may have on generating negative family experiences during transition to care. The study also identified perceptions from families of the important role staff could play in ameliorating, firstly, their sense of failure as primary caregiver, and secondly, the unfamiliarity of their new role in the residential care environment. In the context of change and uncertainty in a new environment, family-staff relationships are a vital component in easing the transition to residential care for the person with dementia (Davies & Nolan, 2004).

Earlier literature in the US established that when a person with dementia enters residential care the difficulty of adapting to the changing environment is compounded by the ongoing cognitive and social decline secondary to the disease process (Kelley & Maas, 1999). Responses to the changing interactions and role transition from home to the new residential care environment also adds to the stress for the family caregiver (Kelley & Maas, 1999). Indeed, although there may be some initial relief from the burden of care, family caregivers report the decision to place a relative with dementia in residential care to be one of the most difficult and painful decisions they have ever made. Primary caregivers often experience additional emotional distress and social disruption both during and after placing their relative with dementia in residential care (Bauer, 2006; Gaugler et al., 2000). In his longitudinal comparison Gaugler, for example, highlighted the persistent effects continuation of distress may have on both family caregiver stress and satisfaction with care (Gaugler et al., 2000).

The views of Gaugler (2000) are supported in a number of studies that examine family caregiver stress and burden of care (Cuijpers, 2005; McGarry Logue, 2003; Nolan & Dellasega, 1999; Toranatore & Grant, 2004). At the time of transition of care the family caregivers' well-being may plummet, as they see their caregiver role eroded and marginalised by staff and they are treated as an outsider in the care of their relative (Maas et al., 2000). The transitional challenges and emotional responses surrounding the changes that occur when a person is institutionalised are difficult to separate from the traumas of the disease process itself, resulting in family-staff conflict (Bauer & Nay, 2003; Scott, Lewis, Loughlin, & Chambers, 2005). Indeed, the major cause of these new stressors as identified by family caregivers is role conflict between family and staff (Gaugler, 2005a; Kellett, 1999). Family caregivers believe that not only is the conflict related to negative staff attitudes towards families, but also their reported difficulty in giving up both their caregiving routine and obligation for caregiving when they place a relative into care (Bauer, 2006). An earlier study by Duncan et al. (1994) points to the importance for families of working with staff to provide emotionally sensitive and personalised care to their relative. In this way families are assured that there is some continuity to the care they were providing at home.

The Importance of Person-Centred Care

Such studies as that by Duncan et al. (1994) have provided an increasing understanding of the needs of the person with dementia, and the opportunity to develop a new environment and culture of dementia care (Kitwood & Benson, 1995). The ground-breaking work by Kitwood (1997) firmly cemented the notion of person-centred care, including respecting the notion of 'personhood' for staff, families and residents with dementia. Kitwood maintained that people with dementia do not stop the process of negotiating and reconstructing an identity for themselves, and that those who care for them can influence, through their own behaviour, the validity of that process in maintaining their sense of identity (Kitwood, 1997). He also argued that as the cognitive decline of dementia advances, interrelationships with family caregivers become increasingly important to maintain some sense of self at a personal and social level. This approach was one starting point for reinforcing the importance of the ongoing family role in the trajectory of care of the person with dementia in residential care (Adams, 1999; Crisp, 1999). It also reinforced the importance of understanding

the notion of 'personhood', not just for the person with dementia but also for family and staff caregivers.

Critics of Kitwood have identified a number of shortcomings in his approach, particularly in relation to its focus on the person with dementia at the expense of the family (Adams, 2005). Other major criticisms are that the initial person-centred model of care lacked empirical support and was too simplistic to understand families and "account for the sorts of negotiations, interdependencies and reciprocities" that characterise partnership models of care (Nolan, Grant, Keady, & Lundh, 2003, p. 273). This understanding is particularly relevant to the issues identified by family caregivers of the importance of their involvement when the person with dementia is admitted to residential care. Nevertheless, the notion of person-centred care continues to provide a sound multidisciplinary basis for enhancing care of the person with dementia and their families (Brooker, 2007). Furthermore, studies continue to expand the notion of family involvement within the context of person-centred care by developing the concept of 'dyadic' (two person) or 'triadic' (three person) partnerships of dementia care (Adams & Moyle, 2007; Davies, 2001; Nolan et al., 2003). In recognition of the importance of the person-centred care philosophy, Alzheimer's Australia has incorporated the requirement for person-centred models of care in their Quality Dementia Care Standards (2007) as a guide both for planning and leadership in delivering quality residential dementia care. Alongside this approach is the requirement for families to be informed about current dementia practice (Alzheimer's Australia, 2007).

Family Involvement in Residential Care

In his synthesis of family involvement literature, US Researcher Gaugler (2005a) describes family involvement as a multidimensional construct that includes visiting, social and emotional support, advocacy and providing personal care (Gaugler, 2005a). Psychosocial-based dementia research continues to provide solid evidence that, although placement in residential care requires a shift in family caregiving, the myth that families leave their relative with dementia to 'die in isolation' has been dispelled (Friedemann, Montgomery, Rice, & Farrell, 1999; Gaugler, 2005a; Maas et al., 2000; Toranatore & Grant, 2004). In reality families seek to play an active role in the care of their relative, and believe they can not only provide beneficial support to staff but

also enrich the person-centred, individualised care for their relative. Furthermore, there is increasing evidence that family caregivers want staff to accept their involvement and take family knowledge into account when making decisions about their relatives' care (Gaugler, Pot, & Zarit, 2007; Reid et al., 2007; Toranatore & Grant, 2004). As aged care nursing research identifies more clearly the views and experiences of families as caregivers within the residential care environment, the benefits to staff of family involvement in improving quality care is becoming more pronounced (McGarry Logue, 2003; Reid et al., 2007).

There is a small but growing body of evidence in Australia and overseas that increased family involvement has a positive benefit for the resident with dementia (Gaugler, 2005a; Haesler et al., 2006; Keady, 1997; Kelley & Maas, 1999; Maas et al., 2004). There is also a small body of evidence that positive family involvement has beneficial impacts for staff through increasing their understanding of the personal needs of the resident with dementia (Maas et al., 2000). However such research reveals that, particularly in the early days of admission to residential care, family involvement can present challenges for families and staff until roles and responsibilities are defined (Bauer, 2006; Hertzberg, Ekman, & Axelsson, 2001; Maas et al., 2000).

In Australia the small body of literature that does exist on family involvement in residential care has highlighted three aspects related to their perceptions of quality of care of the person with dementia: family satisfaction, family stress and resident adjustment (Bauer & Nay, 2003). Similarly, in the US, the limited research on the attitudes of staff to families in residential settings makes strong links between the quality of their relationship with the person with dementia and a positive attitude towards families (Gaugler, 2005a; Gaugler & Ewen, 2005; Zimmerman, Williams, Reed, Boustani, & et al., 2005). Indeed, in their earlier review of the nursing and health literature Australian researchers Bauer and Nay (2003) highlighted the need for further empirical research to increase staff understanding of family-staff partnerships, particularly in residential settings. A qualitative study conducted by Bauer (2006) further confirmed the need for the development of new models in long-term care based on family participation.

As more research reveals the complexity associated with family caregiver roles, there is increasing recognition that spouses of persons with dementia, who may already have seen their caring role eroded during and after residential placement, continue to report significantly poorer well-being compared to offspring (Gaugler et al., 2000; Lieberman & Fisher, 2001; Maas et al., 2000; Robinson, Clare, & Evans, 2005). The conflicting feelings of stress, grief, resistance and guilt are compounded by a sense of failure to fulfil spousal duty (McGarry Logue, 2003). There is evidence to suggest that family caregivers who received emotional support, either from a family or social network prior to residential placement, were less likely to have these negative experiences and thus conflict with staff (Gaugler et al., 2000). However, there continues to be limited understanding of the multi faceted impacts of dementia on family caregiver roles, the longer term effects of caregiver burden and the paths they take over time.

Kellett's (2000, 2006) qualitative, hermeneutic exploration of 14 family caregivers' experiences in Australia highlighted the limited understanding of the complex relationships between family caregivers, residents and staff in long-term care. The research illuminated family caregivers' wishes to be involved in the care of their relative, and the resulting pervasive tension if opportunities were constrained by staff. The study conclusions further emphasised the need for research to focus its efforts on finding ways of increasing family involvement through partnerships with staff (Kellett, 2000; Venturato et al., 2006).

It has been firmly established that most families continue to be involved in the care of their relative with dementia in residential care. Most analyses of family involvement have utilised cross-sectional or qualitative designs to ascertain the dynamics of family involvement (Davies & Nolan, 2004; Hagen, 2001; Mitrani et al., 2006; Toranatore & Grant, 2004). However these study findings are limited as they do not reflect changes in involvement over time, and they ignore the influences that might impact on the well being of family caregivers. More recent studies identify the need to develop and evaluate interventions that have the potential to facilitate and improve effective long-term family involvement in dementia care (Buhr et al., 2006; Gaugler, 2005a; Gaugler & Ewen, 2005; Maas et al., 2004). Furthermore, contemporary research corroborates the view that approaches such as case management, education and psychosocial

interventions are providing good evidence of benefits for family caregivers of persons with dementia (Bower, Rowlan, & Hardy, 2003; Haesler et al., 2006; Levy-Storms & Miller-Martinez, 2005; Woods et al., 2007) . More specifically, there is evidence to support the use of interventions whose content and protocol are more carefully identified so that intervention effects can be clearly specified (Eager, Owen, & Williams, 2007). This view is particularly supported by Gaugler (2005a) in his synthesis and critical review, in which he identifies the importance of adopting empirical longitudinal research designs supported by qualitative research in long-term care. He suggests that such research can assist in addressing some of the challenges in residential dementia care of how best to integrate family involvement into the care of the person with dementia, thus benefiting both family and staff caregivers.

As these studies show, research on the needs of family caregivers of people with dementia is both complex and multidimensional. The majority of the research, both in Australia and overseas, contributes to our understanding of the stressors facing family caregivers during transition to care, and how their satisfaction with care might be improved through increased involvement. However, it is clear from the more recent studies identified in the following tables (as published from the year 2000) that much of the research is qualitative or cross sectional in its approach, limited in its theoretical basis, with small sample sizes in some studies, thus reducing the generality of the findings and providing very little empirical evidence for translation to care practice.

Table 2-1: Summary of Family Caregiver Studies

Authors	Purpose	Variable/s Investigated	Population & sample size	Research Instrument/s	Findings	Limitations
STUDIES ON TRANSITION TO CARE						
Gaugler, Leitsch, Zarit & Pearlin (2000)	To examine the longitudinal relationship between stressors, negative mental health indexes, emotional support and caregivers' nursing home experiences.	Pre placement: stress & support measures Post placement: satisfaction with environment, problems with staff; level of visitation	Family caregivers (n = 185)	Stress process model & instruments	For family caregivers: Stress process has important implications for caregivers throughout nursing home transition.	Information on other potential influences such as environment and staff characteristics not available.
Hagen (2001)	To explore the factors influencing family caregivers to seek residential placement.	Decision-making factors	Family caregivers (n = 5) at home	Four consecutive 45 minute interviews per participant	Factors preventing decision making: Independence; Perceive presence of others; Fear of loneliness; Negative nursing home attitudes; Sense of existential self; Guilt	Small number of participants Formulation of a tentative theory.
Moyle, Edwards, Clinton (2002)	To explore the family caregiver experience after their relative with dementia is institutionalised.	"Can you tell us what it is like to have a relative here?"	Family caregivers (n = 15)	Focus group interviews	Family caregivers continued to experience burden, loss, at times compounded by conflict with staff	Small sample size.
Davies & Nolan (2004)	To identify needs of family caregivers during transition.	Experience of relocation to residential care	Family caregivers (n= 37) at home	Semi-structured interviews	Family caregivers need: More preparation for transition Recognition by staff of their needs More information about dementia	Insufficient empirical evidence to translate to practice.
Buhr, Kuchibhatla & Clipp (2006)	To identify family caregiver reasons for institutionalisation.	Demographics Need for skilled care Caregiver social support Caregiver emotional health	Male veteran family caregivers caring for female spouses (n = 570) at home	Behaviour Rating Scale Dementia (BRS-D) Instrumental Activities of Daily Living (IADL) Multidimensional Functional Assessment Questionnaire Duke Social Support Index	Major reasons for institutionalisation. Need for skilled care (65%) Caregiver's health (49%) Need for professional assistance (23%)	Use of self-reported data only Not generalisable to population due to limited demographics of sample.
Mitrani, Lewis, Feaster, Czaja et al. (2006)	To evaluate the role of family functioning in disease burden prior to institutionalisation.	Demographics Burden Depression Anxiety Perceived health	Family caregivers (n = 189) at home	Depression scale State-Trait Anxiety Inventory Perceived Physical Health Screen for Caregiver Burden	Family caregiver burden and distress can be mitigated by improved family functioning prior to institutionalisation.	Cross sectional framework does not capture dynamics of families.

Table 2-1: Summary of Family Caregiver Studies Cont'd

Authors	Purpose	Variable/s Investigated	Population & sample size	Research Instrument/s	Findings	Limitations
STUDIES ON CAREGIVER BURDEN						
Cuijpers (2004)	To examine the prevalence of depressive disorders in caregivers of people with dementia.	Systematic literature search	Ten studies of caregivers (n = 790)	Systematic literature review	High prevalence of depressive disorders in family caregivers of people with dementia.	Studies conducted in UK and US only. Small, unrepresentative study samples. Types of caregiver not identified.
Scott, Lewis, Loughlin & Chambers (2005)	To develop an understanding of how dementia challenging behaviours impacts on family caregivers.	Caregiver views & experiences of caring for a relative at home.	Thirteen family caregivers	Focus groups	Families need more support from community mental health nurses to understand behaviours in context	Sample not representative.
STUDIES ON CAREGIVER SATISFACTION						
Tornatore & Grant (2004)	To examine what contributes to family caregiver satisfaction as a means of implementing quality improvement.	Caregiver satisfaction related to primary objective stressors	Family caregivers (n = 285)	Stress process model & instruments	Higher satisfaction associated with: Stage of dementia, length of time caregiving prior to institutionalisation, higher visitation, greater expectation of care.	Cross sectional data does not allow for variables to be tested & new measures need to be validated. Family involvement scale does not capture complex nature of family involvement.
Levy-Storms, L Miller-Martinez, D (2005)	Examine the relationship between caregiver involvement and satisfaction with institutional care in first year.	Demographics Satisfaction Caregiver involvement Depression Family tension	145 family caregivers of residents with dementia admitted for less than one year	Satisfaction measure Caregiver involvement measure Caregiver depression measure Family tension measure	More involved caregivers were less satisfied at admission and became more dissatisfied during the year following admission.	Satisfaction measured technical care delivery rather than family involvement. Did not include psychosocial aspects of person-centred care.

Table 2-1: Summary of Family Caregiver Studies Cont'd

Authors	Purpose	Variable/s Investigated	Population & sample size	Research Instrument/s	Findings	Limitations
STUDIES ON FAMILY INVOLVEMENT						
Lieberman & Fisher (2001)	To determine the effects of nursing home placement (NHP) on family caregivers, compared to remaining in the community over 2 year period.	Caregiver health and wellbeing	239 family caregivers 89 spouses 184 offspring 136 in-laws	197 item questionnaire measuring physical symptoms, somatic complaints & anxiety / depression	No significant differences in wellbeing of NHP family caregivers compared to community. No significant change in NHP family caregiver wellbeing over time.	Does not include how the context of care affects post-NHP family caregivers over time.
Gaugler (2005)	To critically synthesise existing literature on family involvement in long term residential care.	The multi-dimensional construct of family involvement	Relevant literature from 1988 to 2005	Literature review	Future studies should adopt longitudinal designs that provide direct empirical links through evaluation of outcomes.	Insufficient empirical evidence to translate to practice.
Bauer (2006)	To examine how nursing home staff experience working with families.	How staff constructed the role of families & family involvement	30 staff members from metropolitan & rural facilities	Face to face interviews (2001/02)	Some nursing staff adopted family-friendly practices. Conflict & adversarial role with families evident. Divide between staff attitudes and practices & political rhetoric of participatory family care.	Does not include family views of their involvement.
Kellett (2007)	To explore how family members seize possibilities to be involved in residential care.	Positive aspects of family involvement	14 family caregivers	Face to face interviews	Accommodating new ways of caring Feeling a part of nursing home Seeing the whole picture Learning to seize new possibilities	Small number of participants.
Reid, Chappell & Gish (2007)	To develop measurements of family involvement in long-term care.	Family perceived involvement Assessment of importance of involvement	Families of residents in 6 long-term care facilities	Family perceived involvement questionnaire Importance of involvement questionnaire	Families will remain involved in care if actively encouraged by facility staff & policy. Involvement (or lack of it) precedes satisfaction. Depth of involvement by families must be matched by depth of facility commitment.	More work required to develop instruments.

Table 2-1: Summary of Family Caregiver Studies Cont'd

Authors	Purpose	Variable/s Investigated	Population & sample size	Research Instrument/s	Findings	Limitations
STUDIES ON FAMILY-STAFF PARTNERSHIPS						
Nolan et al. (2003)	To promote a relationship-centred approach to care.	The dynamics of family/staff caregiver relationships	Family caregivers	The senses framework	Relationship-centred approach provides potential framework for understanding dynamics of family-staff partnerships.	No measurement tools developed to provide empirical evidence.
Pillemer et al. (2003)	To increase communication & cooperation between family members and nursing home staff.	Interpersonal conflict Staff empathy Family caregiver burden	932 family members 655 staff members	Interpersonal conflict scale Staff/family behaviours scale Staff/family empathy scale Family Caregiver burden Staff burnout/intention to quit	Less family-staff conflict Improved staff & family attitudes Lower likelihood of staff intention to quit	Insufficient follow up training for staff & families Unable to link research to policy and procedural changes
McGarry Logue (2003)	To discuss how research can be used to develop an advance practice family nursing role in long-term care.	Existing research on developing a “family as client” approach to care	Relevant literature from 1982 to 1999	Literature review	Families contribute to: quality assurance enhanced clinical decision making, and more rewarding long-term environment for staff and residents.	Insufficient empirical evidence to translate to practice
Bauer & Nay (2003)	To review the last 20 years of literature on family-staff partnerships in long term care.	Family involvement in care	Relevant literature from 1982 to 2002	Literature review	Most caregivers want to remain involved. Staff need to allow families to make choices about their role and level of involvement.	Insufficient empirical evidence to translate to practice
Haesler, Bauer & Nay (2006)	To present evidence on strategies, practices and organisational characteristics that promote family-staff relationships.	Literature search to identify qualitative and quantitative research in aged care	Papers reviewed by independent panel for methodological quality	Joanna Briggs Institute appraisal forms for data extraction	Families want involvement in care. Staff expressed support but did not translate to practice.	Small sample groups, use of volunteer participants, from high socioeconomic background, lack of person with dementia’s voice.

The Effects of Dementia Caregiving on Staff

Chapter One clearly identifies the increasing prevalence of persons with dementia in residential care, and the increasing difficulties in attracting suitable staff to care for them. As the residential aged care environment continues to experience structural and organisational changes over which staff have very little control, including increases in unlicensed care staff, it becomes even more crucial to address the issues associated with staff stress and job dissatisfaction. It has been shown in nursing generally that job satisfaction is a significant salient influence on retention of staff and that constant organisational change may have a pronounced detrimental effect on staff performance (Jackson et al., 2002; Sikorsda-Simmons, 2005). However, despite attempts in several major reports in Australia to address staffing issues in aged care, attrition of RNs from the industry continues to rise (Cheek, Ballantyne, Jones, Roder-Allen, & Kitto, 2003; Eley et al., 2007; Jackson et al., 2002; Moyle et al., 2003; Richardson & Martin, 2004; Venturato et al., 2006, 2007). At the same time, overseas, a number of research studies attempt to address the problem by specifically examining the effects of dementia caregiving on staff in residential care.

In Australia the cross-sectional design study conducted by Brodaty et al. (2003) provided evidence that staff in nursing homes perceived residents with dementia in more negative than positive ways. The majority of staff were satisfied with their work, however the relationship between satisfaction and other influences such as resident behaviour, organisational uncertainty, provision of education, training and support for nursing staff were not established. It was concluded that missing demographic data, inadequate instrument measures and inability to calculate the response rate limited a comprehensive identification of factors that contribute to staff strain and satisfaction. Brodaty's study highlights the complexities associated with dementia caregiving and the challenges of identifying clearly what might be the major factors associated with staff stress, job satisfaction and care standards.

The findings of the Brodaty et al. (2003) research were supported by the qualitative study undertaken by Moyle et al. (2003), which confirmed that, overall, staff working in long-term care found their work satisfying. In this study the major influences on

job dissatisfaction were identified as inadequate staffing levels and associated pressure to work overtime, tensions related to role expectations, and working with inappropriately trained staff (Moyle et al., 2003). A survey conducted by Hsu et al. (2005) in 70 long-term care facilities in Queensland, Australia, provided further insight into the needs of aged care staff. It concluded that continuing education with a focus on mental health, including dementia and its disabilities, would positively influence the standard of care provided to meet the needs of residents (Hsu et al., 2005).

The descriptive study undertaken in the US by Zimmerman et al. (2005) considered in detail the dementia related attitudes of front-line care staff working in a range of residential care settings. Work stress and satisfaction measures were examined from data collected from 154 direct care providers (nurse aides and personal care aides) in 41 long-term facilities in the US. As in Australia the research was driven by the need to address increasing staff attrition from care facilities in which the proportion of persons with dementia continues to rise. Previous studies in the US had focussed on factors such as dementia severity of residents, staff-to resident ratios and staff training to provide an explanation for the increased stress in residential care generally. This study provided an additional group of factors seen as relating specifically to the specialised [dementia] care unit (SCU); for example uncooperative residents, complaining or emotionally demanding families, understaffing, inexperienced co-workers, dissatisfaction with workflow and unmet expectations. Staff attitudes towards families is discussed in more detail in the next section. The study findings reveal a strong positive link between ongoing training and reduced staff attrition. The most notable finding is evidence of the strong relationship between knowledge of person-centred care, quality of care and staff satisfaction (Kitwood, 1997; Zimmerman et al., 2005).

As dementia-specific care becomes a focus in long-term care, more recent studies examine the relationship between residential dementia caregiving in SCUs and staff job satisfaction with varying results (Morgan et al., 2005; Pekkarinen et al., 2006; Robinson & Pillemer, 2007). Whilst there are indications that staff in SCUs report higher job satisfaction, the significant influencers are more clearly defined as their relationships with families, co workers and supervisors. The study by Robinson and

Pillemer (2007) makes the link between the focus on the interpersonal environment provided in the SCU and the importance of positive relationships with families in improving job satisfaction. On the other hand, Pekkarinen et al. (2006) claims that SCU staff who are not sufficiently trained in dementia care report higher levels of stress and job dissatisfaction than in long-term care generally. He concludes that, with sufficient staff training, the behavioural problems associated with dementia are less associated with SCU staff stress than in residential care generally. These findings support previous research that a culture of support and innovation that mediates the effects of burn-out is more likely to be found in a SCU than in the aged care facility generally (Maas, Swanson et al., 1994; Mobily, Maas, Buckwalter, & Kelley, 1992). Specialist staff training in dementia care was found to be a critical factor in allowing staff to cope with the stressors inherent in their daily work (Mobily et al., 1992).

McGilton and McGillis' (2007) cross-sectional design study undertaken in Canada builds on our knowledge of the stressors for care staff working in long-term care by investigating the effects of supervisory support provided by registered nursing staff on job stress and satisfaction. However, a number of limitations to the study were noted, particularly the disparities in the findings caused by staff's ethno-cultural background, first language spoken and self-selection bias in the self-report measures. The researchers concluded that further longitudinal studies are necessary to clarify the links between organisational issues and staff and patient outcomes (McGilton & McGillis, 2007). Recent studies on health care generally continue to highlight the importance of organisational culture and its effect on the well being of both staff and family caregivers (Mary & Melanie, 2006; Way & MacNeil, 2006).

The study conducted in Sweden by Hasson and Arnetz (2006) raises the issue of disparities in staff knowledge in aged care generally, and more specifically in dementia care. Staff participants in the study rated their own knowledge and competence levels and identified significantly less knowledge levels in community care compared to residential care. Whilst it was also found that staff working in community care rated the physical demands of their work more positively, the finding raised some issues about the lack of dementia-specific psychosocial support and person-centred care being provided to persons with dementia at home. The study emphasised the need for staff working in community care to have the required skills

and knowledge to provide continuity of care to persons with dementia and their families.

Reports in Australia support this view by identifying the importance of providing more education and training programs for all staff in aged care, and more opportunities for increasing involvement with informal carers (Hogan, 2004; Jackson et al., 2002; Productivity Commission, 2008; Richardson & Martin, 2004). Such programs would provide continuity between the community and residential care environments in long-term care, improve staff knowledge of dementia care and enhance relationships between staff and families. A key aspect of such education programs is firstly to identify leaders, whether they be RNs, EENs or other health professionals, who are competent in supervision, allocating resources and staff development in a person-centred dementia care framework (Alzheimer's Australia, 2007; Brooker, 2003).

Staff-Family Relationships in Long-Term Care

During the past decade international research has shifted its focus from examining family caregiver needs in the community to that of residential care. Integral to the research is the acknowledgement in dementia care of the importance staff attitudes play in responding to family caregiver needs. The research conducted in the US by Gaugler and Ewen (2005) in five nursing homes, five assisted living facilities and sixteen family care homes aimed to examine staff attitudes to family members across the continuum of long-term care. The Attitudes Toward Families Scale developed by Maas et al. (2000) was used to measure staff perceptions of primary family members, together with demographic and descriptive data. The findings suggest that staff valued family members' inclusion in the resident's life, although attitudes about family involvement in residents' care were less certain (Gaugler & Ewen, 2005). In the context of the literature already discussed it is clear that staff's attitude to involving families in care is influenced by the culture of interpersonal relationships within the organisation, their level of knowledge about dementia care and the stresses of their individual workload (Brodaty, Green et al., 2003; Robinson & Pillemer, 2007). Gaugler's (2005) findings emphasise the need to further understand the role of

staff attitudes in formalising family involvement and what is meant by the notion of partnerships in long-term care (Gaugler & Ewen, 2005).

Bauer's (2006) Australian qualitative study of nursing home staff members used naturalistic inquiry to explore their experiences of staff-family relationships. The findings raise the issue that although in theory families are seen as integral to residential facilities, the notion of partnerships was more commonly observed as rhetoric rather than a working collaboration. This is despite the recognition both in the Charter of Residents' Rights and Responsibilities (Commonwealth Department of Health and Aged Care, 2002) and the Australian Government Aged Care Standards of Practice (Commonwealth Department of Health and Aged Care, 2001) that family members are entitled to assist with and attend to their relative's care and well-being. Nevertheless, the findings in this study reveal that although some nursing staff members have adopted a range of family-friendly practices, most staff, including unlicensed staff who are in the majority, are not trained to work in a collaborative fashion with families (Bauer, 2006).

Bauer's findings were supported by Haesler et al. (2006) in their systematic review of family-staff relationships in residential care in Australia. The review provided evidence that although staff supported family involvement in care, this often did not translate to clinical practice. Instead, staff were more frequently guided by the traditional biomedical models of care and aimed to maintain control over their environment. The review identified four major success factors to achieve collaborative family-staff partnerships: communication, information, education and administrative support (Haesler et al., 2006). The review also identified that family members most at stress and therefore most likely to benefit from a partnership intervention in residential care, were older relatives or spouses of the resident with dementia. Staff most likely to benefit from effective family-staff relationships were identified as those with lower educational backgrounds whose communication skills and confidence with families are limited. This cohort of staff caregivers is increasingly caring for residents with dementia as the numbers of trained staff dwindle. The review presents evidence on the success of strategies that promote family-staff relationships by examining interventions that include organisational driven strategies, formal staff-family meetings and case conferences, and

environmental approaches (Haesler et al., 2006). The review concludes that models of care based on family-staff collaboration, support for staff education and administrative support are more likely to provide benefits for all parties. Such models of care have the opportunity to develop dynamic, working partnerships between the person with dementia, family and staff caregivers.

Developing Partnership Models of Care

In Australia and overseas, nursing partnership models of care are developing in response to the need for working relationships that might deliver solutions where single agents have failed (Aveyard & Davies, 2005; Clarke, 1999; Woods et al., 2007). Since the 1980s there has grown a small body of aging research and literature overseas on partnership models of care (Nolan & Dellasega, 1999; Robinson, Curry, Gruman, & Porter, 2007; Ward-Griffin & McKeever, 2000). However, there remains little written about how these relationships may develop in nursing and health care in general (Ward-Griffin & McKeever, 2000). In residential dementia care, partnership models are defined as those with an emphasis on developing collaborative roles between family and staff (Gaugler & Ewen, 2005). Studies suggest that, historically, partnership programs have focussed on family needs, ignoring the needs of staff in developing workable relationships (Pillemer, Sutor, Henderson, & Meador, 2003). Furthermore, some dementia research shows that staff fail to call on the comprehensive personal knowledge families have about their relative with dementia (Aveyard & Davies, 2005; Duncan & Morgan, 1994). These findings highlight the complexities of caring for the person with dementia, the confusion that may result about family and staff roles and responsibilities, and the emerging family-staff conflict in the absence of negotiation about care.

In residential aged care, family-staff partnerships are described as a complex mix of interactions between the person with dementia, the family and staff caregivers (Aveyard & Davies, 2005; Bauer & Nay, 2003). Some researchers have hypothesised that a major barrier to the development of meaningful partnerships between families and staff is the lack of acknowledgement as to each other's knowledge about dementia and dementia care (Maas et al., 2001; Phyllis, 2003). Nolan, Grant & Keady (1996) explored another previously neglected dimension of care - sources of family caregiver satisfaction, with the view that understanding the tension between burden and

satisfaction may provide some insight into more successful care planning. As discussed previously, it may be possible to improve staff and family caregiver satisfaction as a result of interventions implemented by health professionals in the community setting. Whilst to date there is very little evidence that interventions that attempt to reduce caregiver burden have any positive impacts, those with a focus on improving caregiver perceptions, and well-being as a measure of satisfaction with care, have provided some evidence of success (Nolan, Ingram, & Watson, 2002),

The Partnership in Caregiving (PIC) study conducted in the US, which involved 932 families and 655 staff from 20 nursing homes, implemented a training program designed to improve family and staff relationships in nursing homes generally (Pillemer et al., 2003). The effects of the PIC intervention, derived from theoretical and empirical research on interpersonal interactions, did find improvements in family and staff members' perceptions of each other immediately following the intervention. However the study revealed a number of limitations in relation to the intensity of the treatment effect, measurement of benefits on residents and tracking of any structural or policy changes in the residential facilities (Pillemer et al., 2003).

A subsequent study based on the PIC was undertaken by US researchers Robinson et al. (2007) specifically in a SCU. Based on the results of the previous study the PIC program was modified to become the Partnership in Caregiving in a Special Care Unit (PIC-SCU). This study (388 family members and 384 staff members from 20 nursing homes) reported positive demonstrated effects for families, staff and residents. The components of the PIC-SCU program consisted of: parallel family and staff training on effective communication and conflict resolution; a section on how cultural, racial and other differences (eg socioeconomic status) may affect communication; and a comprehensive training manual detailing directions for facilitating sessions. Evaluations from both family and staff who participated in the program were consistently positive, as were the beneficial treatment effects for families (Robinson et al., 2007). However the PIC framework requires rigorous testing and development to evaluate its success in the longer term and in its application at policy level as a model of care in the residential dementia care environment (Robinson et al., 2007).

In summary, the literature highlights the need for theory driven, longitudinal design studies that follow the family caregiver's progress through the milestones of the dementia caregiving process and the changing levels of care (Levy-Storms & Miller-Martinez, 2005; Mitrani et al., 2006; Toranatore & Grant, 2004). It is clear that promoting family involvement with staff caregivers over time allows for adaptation to changing roles for the family and their relative with dementia. However, studies conducted to date have highlighted the major limitations of intervention research for caregivers in dementia care as the difficulties in alleviating stress and burden, problems with staff attrition and therefore continuity, and the heterogeneous nature of the participant sample (Jablonski, Reed, & Maas, 2005; Zarit & Femia, 2008).

There continues to be a dearth of literature available that reports on the best practice of partnership models for families of people with dementia in residential care. During the past two decades one partnership model of care, entitled Family Involvement in Care (FIC), has provided strong evidence of its success in the context of specialised dementia care. The strength of the FIC intervention, as identified in the US research (hereafter referred to as Maas et al.) is its focus on promoting and maintaining the health of family caregivers through education and meaningful exchange with staff caregivers (Maas et al., 2000). As identified in the UK research (Nolan et al., 2004), this notion of partnership between families and staff derives from the view that families themselves are clients and a potential resource for improving the resident's quality of care (Maas, Buckwalter et al., 1994). Thus the FIC model of care was systematically developed in response to research that demonstrated dissatisfaction of family member roles in providing care in the residential care setting (Maas, Buckwalter et al., 1994). The three major areas of dissatisfaction identified by family were lack of involvement with resident care, disagreement over the use of formal services and activities, and lack of acknowledgement as a caregiving resource (Maas, Buckwalter et al., 1994).

Overview of the Family Involvement in Care (FIC) Research

The FIC Family Involvement Model of Care was initially developed by a team of researchers from the University of Iowa, US, in response to the increasing prevalence of persons with dementia admitted to residential care. Until this time an abundance of research studies had focused on family caregiving in the community setting, but little

was known about the needs of family caregivers following admission of their relative to residential care (Mason, Wilkinson, Moore, & McKinley, 2003). A summary of the FIC research, as it developed from 1989 to 2000, is presented in Table 2.1.

The earlier studies conducted by the University of Iowa research team aimed first to increase understanding about the impacts of dementia on family caregiver burden and stress following admission of their relative to residential care. The second aim of the earlier studies was to determine the relationship between family and staff caregivers and whether this played a critical role in family perceptions of care in the formal care setting (Maas et al., 1991). The first phase of the study consisted of collecting data on family perceptions of care of their relative with dementia every second month over a 12 month duration using the Family Perceptions of Care Tool developed by Maas and Buckwalter (1989). The study findings, published by Maas et al. in 1991, revealed that the majority of families continued to have frequent contact with their relative with dementia through visitation and making contact with a staff member (Maas et al., 1991). The second phase of the study, published by Mobily et al. in 1992, evaluated the effects on staff stress levels of working on a newly opened specialised Alzheimer's Unit or, as it became known, a Special Care Unit (SCU). The staff from the SCU who comprised the treatment group received 80 hours of specialised training. The control group consisted of staff who worked in traditional aged care facilities. The findings suggested that staff on the SCU experienced a significant reduction in stress as measured by the subscale reflecting staff knowledge, ability and resources, and there was a tendency towards less burnout (Mobily et al., 1992).

The results of the research, discussed in the first of two articles published by Maas et al. in 1994, highlighted the need for the development of more 'structured environmental strategies' for people with dementia, which would address the problems associated with cognitive impairment (Maas et al., 1994, p 173). As a result of the findings, SCUs continued to evolve as specialised environments suitable for residents with dementia, with their roots in Powell Lawton's person-environment fit model (Powell Lawton & Herzog, 1989). Maas and colleagues identified that family involvement in care was crucial to the strategic development of the SCUs, and recommended specifically designed interventions to encourage this strategy.

Accordingly they recommended ongoing research and evaluation of family, staff and resident outcomes as indicators of quality of care (Maas, Swanson et al., 1994).

The subsequent article published by Maas et al. in 1994 introduced a partnership strategy based on the person-environment fit model, designed to address the areas of family dissatisfaction and staff stress identified in their previous research. The aims of the partnership therefore were not only to improve family satisfaction through more involvement in care and improved functional outcomes for residents with dementia; it also aimed to reduce staff caregiver stress. Funding had been granted by the National Institute of Nursing Research (NINR) and pilot testing of the FIC partnership intervention began. Testing of the reliability and validity of the family, resident and staff outcome measures also commenced. It was determined that a quasi-experimental, repeated measure design would be employed to test the effects of the intervention over time (Maas, Buckwalter et al., 1994). The intervention was conducted in fourteen nursing homes with designated SCUs, seven of which were designated as control sites and seven as intervention sites (see Table 2.1).

Three years later, Buckwalter, Maas and Reed's 1997 paper supported previous claims that there was a scarcity of empirical literature available on family and staff caregivers in residential care settings, particularly dementia specific SCUs. The article initially makes a number of assumptions based on the premise identified in their previous research that resident, family and staff outcomes influence each other dynamically. Firstly it is assumed that the outcomes, therefore, are difficult to separate from each other. The authors then argue for the development of interventions in residential settings that are theoretically grounded, so that sense can be made of the outcomes measured and instruments can be developed for clinicians as well as researchers. They then raise the issue of 'relation to context' and argue for the need to develop instruments based on experiences specific to family and staff caregivers of persons with dementia within and between various community and residential settings (Buckwalter et al., 1997). Finally they contend that more coordinated longitudinal studies are required to determine the impact of interventions over time.

As a consequence a qualitative study was conducted with the aim of describing family members' experiences when visiting their relatives with dementia on SCUs (Kelly,

Swanson & Maas 1999). The qualitative findings originated from a randomly selected sample of 30 family caregivers participating in the larger FIC study. The participant sub-sample was interviewed at baseline prior to the implementation of the FIC intervention. The researchers used a semi-structured interview guide consisting of four content areas related to pre placement and placement issues described as: 1) care provided for the person with dementia at home, including how the diagnosis of dementia was made; 2) the process and feelings associated with placing the person with dementia in the SCU; 3) perceptions of their relationships with staff and the resident and 4) evaluation of care on the SCU.

The qualitative findings published by Kelley and Maas (1999) focussed on describing family experiences of factors related to post-placement in residential dementia care only, with the view to increasing understanding of what family involvement in SCUs may mean. The major finding of the research served to extend the evidence that families do not relinquish their caregiving role after residential placement. The research identified that they take on a different role within the SCU, aimed at assuring their relative's personal well being and continuing the sense of family with their relative. The qualitative findings also served to support development of the person-environment and role theory framework in the still little known area of family caregiving in SCUs by providing additional guidance for staff in promoting a more interactive environment for fostering family involvement (Kelley & Maas, 1999).

A second article published by Kelley et al. (1999) aimed to examine and disprove three assumptions held by society about social expectations of family caregiving of persons with dementia in the community setting. The first assumption was that families are not providing enough care, the second that families know how to provide care, and the third that families have access to resources for provision of care. Critical analysis of these assumptions through examination of the literature raised major issues for the person with dementia in relation to neglect, abuse and ill health. Hence the assumptions were refuted and options to assist family caregivers provide better care for their relative were discussed, such as access to caregiver education, training and support resources (Kelley, Buckwalter, & Maas, 1999).

In 2000, six years after the commencement of the FIC pilot testing, the final Maas et al. report from the University of Iowa was completed detailing the FIC intervention and outcome effects for families and staff caregiver participants. A nine month trial was completed with family caregivers, including two pre-test and three post-test data collections. Staff data were collected, once pre-test and every six months post-test, for a period of two years. Due to lack of significant change in inappropriate behaviour, cognition and functional status, data from resident participants were not presented until a later paper in 2005 (Jablonski et al., 2005). Based on this study the FIC intervention was added to the Nursing Interventions Classification (NIC) (Iowa Interventions Project 1996) and the Nursing Outcomes Classification (NOC) (Iowa Outcomes Project, 1997) (Maas et al., 2000). The researchers were now in a position to achieve their aim of formalising the FIC model of care and make it available for other researchers and clinicians in residential care. The purpose of the subsequent article published by Kelley et al. (2000) was to provide an account of the FIC intervention guidelines for involving family caregivers with formal staff caregivers through partnerships. The notion of the partnership, defined as a ‘cooperative role relationship’ was explored, as was the essence of the FIC intervention, described as:

“... negotiation, clarification, and establishment of mutually satisfactory role expectations for family caregiver(s) and formal care providers, assisting them through role and environmental transitions to accomplish the needed care.”
(Kelley et al., 2000 p15).

The components of the FIC protocol were clearly established and made available to other researchers and clinicians. The FIC education resources required to implement the FIC intervention, including the Education Resource Manual for families and an outline of the staff education objectives were also detailed (Pringle Specht et al., 2000). The second article published by Pringle Specht et al. in 2000 compared two sub-samples of the larger FIC study to identify cultural differences in knowledge, stress and satisfaction between Caucasian and African-American family caregivers. Implications from the sub-sample findings supported the previous conclusions that family caregivers want to remain involved in the care of their relative with dementia. However, follow up and monthly contact between staff and families was problematic,

compounded by professional and direct care staff turnover, particularly in the African American RCFs (Pringle Specht et al., 2000).

An overview of the FIC qualitative and quantitative findings, presented by Maas et al. (2001), identifies positive intervention effects for family and staff caregivers. In particular the FIC intervention improved feelings of loss and guilt for family caregivers who were spouses of the person with dementia. Staff attitudes towards families were also positively affected, providing benefits of maximising exchange of information about residents and enabling greater family involvement (Maas et al., 2001). Beneficial outcome effects were identified in three of the four areas of family caregiver outcomes, and one of the four areas of staff caregiver outcomes. Specifically, the intervention had significant beneficial effects on family caregivers' feelings of loss and captivity, and improved their perceived relationships with staff caregivers and residents. For staff the interventions produced more favourable perceptions of their relationship with family caregivers (Maas et al., 2004).

The next publication by Pringle Specht et al. (2005) provided an in-depth description and evaluation of the six main instruments used to test the FIC intervention. The article highlighted the usefulness of SCUs in caring for and improving disruptive behaviours of residents with dementia compared to traditional RCFs. However, it also emphasised the need for ongoing systematic testing of the FIC intervention, addressing research questions using the appropriate psychometrically sound instruments for the identified population. The researchers highlighted that following each of their studies, instrument development or modification was required and undertaken (see Tables 3.3 and 3.3). The most recent Maas et al. article published in 2005 examined the effect of the FIC intervention on functional and cognitive status of the 164 residents with dementia whose family caregivers participated in the study (Jablonski et al., 2005). Although the study findings did identify a slow down in overall deterioration for dementia residents in the treatment group, the effects on self-care ability, inappropriate behaviour and agitation were inconclusive. These findings confirmed the challenges and complexities of measuring beneficial outcomes that may halt the progression of the symptoms of dementia (Jablonski et al., 2005).

A summary of the Maas et al. research development is presented on the following pages.

Table 2-2 : Summary of Family Involvement in Care (FIC) Studies

Authors	Purpose	Variable/s Investigated	Population group and sample size	Research Instrument	Findings	Limitations
Maas, Buckwalter & Kelley (1991)	To increase understanding of how family caregivers perceptions of care are influenced by their own feelings, as well as their relationship with staff.	Family satisfaction with care	A residential facility and a community facility. Family members (n = 40) and significant friends (n = 9).	Family Perceptions Tool (Mass & Buckwalter, 1989)	Family satisfaction with nursing care reduced over time. Family satisfaction with the environment remained high.	Small sample size High attrition of family caregivers.
Mobily, Maas, Buckwalter & Kelley (1992)	To explore factors influencing staff stress on a specialist Alzheimer's Unit (SCU) following training.	Staff stress	Care staff in Alzheimer's Unit. Care staff who received 80 hours of specialised training (n = 12)	Caregiver Stress Inventory (CSI) Maslach Burnout Inventory (MBI)	Stress and burnout tended to decrease on the SCU compared to the control subjects in the areas of staff knowledge, abilities and resources.	Staff did not complete questionnaires at each time period. Small sample in treatment group (n = 15).
Maas, Swanson, Specht & Buckwalter (1994a)	To identify the importance of developing appropriate Special Care Units (SCU's) for people with dementia.	Person-environment fit model	SCU residents, families and staff	Instruments that distinguish the features of SCU's indicative of quality care.	Work in progress	In testing phase.
Maas, Buckwalter, Swanson, Specht, Tripp-Reimer & Hardy (1994b)	To develop a strategy to increase family & staff cooperation when caring for residents with dementia.	Family, resident and staff well being	Pilot testing of intervention and instruments	Under development	In testing phase	In testing phase.
Kelly, Swanson & Maas (1999)	To describe the meanings families attach to their experiences when visiting relatives on SCUs.	Family experiences post placement of their relative with dementia	Family caregivers participating in FIC study (n = 30) at baseline, prior to intervention	Semi-structured interviews within 5 content areas related to caregiving	Family caregivers shift their role post placement from one of providing care to one of monitoring	Predominance of white, female informants.

Table 2-2: Summary of Family Involvement in Care (FIC) Studies Cont'd

Authors	Purpose	Variable/s Investigated	Population group and sample size	Research Instrument/s	Findings	Limitations
Kelley, Specht & Maas (2000)	To give an account of the FIC protocol, to define the partnership and identify resources.	N/A	Family and staff caregivers participating in FIC study	FIC Intervention	N/A	N/A
Specht, Kelley, Manion, Maas, Reed & Ratz (2000)	To highlight differences in strategies and findings between two ethnic groups.	Family & staff knowledge, stress & satisfaction Resident cognitive & functional status (not reported)	Sub sample (n=47) of larger FIC study: 5 RCFs with Caucasian subjects 2 RCFs with African American subjects	Family Perceptions of Care Tool (FPCT) Family Perceptions of Care Role (FPCR) Knowledge of Alzheimer's Test (KAT)	Significant differences in knowledge & satisfaction between groups	Lack of co ordinator time to meet with families & update partnership agreements Low staffing levels.
Butcher, Holkup, Park & Maas (2001)	To provide an in depth description of the experience of family caregivers of making the decision to place their relative with dementia in residential care.	Family experiences of the decision making process	Family caregivers participating in FIC study (n = 30) at baseline, prior to intervention	Semi-structured interviews within 5 content areas related to caregiving	Ill prepared to make the decision Feelings of guilt & betrayal Seek reassurance through monitoring care	Predominance of white, female informants.
Maas, Reed, Specht, Swanson, Tripp-Reimer, Buckwalter, Schutte & Kelley (2001)	To present the qualitative and quantitative findings of the FIC intervention at baseline & follow up.	Family experiences Family stress & satisfaction Staff stress & satisfaction	Family caregivers (n = 185) Residents with dementia (n = 165) Staff caregivers (n = 845)	Families – FPCT; FPCR; KAT Residents – N/A Staff - GJS*; SPCR**; CSI ⁺ ; AFC ⁺⁺	Positive effects for: Families – guilt, loss reduced Staff – attitudes towards families	Insufficient leadership & commitment from staff.

General Job Satisfaction; ** Staff Perceptions of Caregiving Role; ⁺ Caregiver Stress Inventory; ⁺⁺ Attitudes about Families Checklist

Table 2-2: Summary of Family Involvement in Care (FIC) Studies Cont'd

Authors	Purpose	Variable/s Investigated	Population group and sample size	Research Instrument/s	Findings	Limitations
Maas, Reed, Park, Specht, Schutte Kelley, Swanson, Tripp-Reimer & Buckwalter (2004)	To report family and staff caregiver findings using hierarchical linear modelling to test the FIC intervention effects over time.	Family stress & satisfaction Staff stress & satisfaction	Family caregivers (n = 185) Staff caregivers (n = 845)	Families – FPCT; FPCR; Staff - SPCR**; CSI ⁺ ; AFC ⁺⁺	Positive effects for: Families – 3 of 4 outcome areas Staff – 1 of 4 outcome areas	Family & staff sample ethnically homogenous. Intervention effect fell short of establishing partnership Fewer positive effects for younger generation.
Specht, Park, Maas, Reed, Swanson & Buckwalter (2005)	To describe six FIC instruments, their psychometric properties and their advantages for residents with dementia.	Family stress & satisfaction Staff stress & satisfaction Resident cognitive & functional status	Residents with dementia in residential care Family and staff caregivers	Families – FPCT; FPCR; Staff - SPCR**; CSI ⁺ ; AFC ⁺⁺ Residents – Functional Abilities Checklist (FAC)	N/A	FAC not stable across baseline and post-test intervals.
Jablonski, Reed & Maas (2005)	To examine the effects of the FIC intervention on cognitive and functional ability of older adults with Alzheimer's Disease & related dementias.	Family & staff knowledge, stress & satisfaction Resident cognitive & functional status (not reported)	Sub sample (n=47) of larger FIC study: 5 RCFs with Caucasian subjects 2 RCFs with African-American subjects	Family Perceptions of Care Tool (FPCT) Family Perceptions of Care Role (FPCR) Knowledge of Alzheimer's Test (KAT)	Significant differences in knowledge & satisfaction between groups	Lack of co ordinator time to meet with families & update partnership agreements. Low staffing levels.

General Job Satisfaction; ** Staff Perceptions of Caregiving Role; ⁺ Caregiver Stress Inventory; ⁺⁺ Attitudes about Families Checklist

The FIC Intervention in Context

During the 1990s the development of the FIC research occurred in the US in parallel with the establishment of the National Institute of Nursing Research (NINR), the major funding body for the project. This was also the time of the inauguration of the Cochrane Collaboration which updates systematic reviews of clinical interventions to facilitate Evidence Based Practice. Hence the FIC intervention, through its theoretical framework, rigorous methods and multiple confirmation strategies, created a strong evidence base for replication (Polit & Beck, 2008). To this end, following the finalisation of the Iowa Family Role Trials (see Table 2.3), a partial replication study was completed in Korea (Park, 2001; Pringle Specht et al., 2005).

In order to measure family and staff caregiver outcomes of the FIC, the Maas et al. research team continued to conduct systematic testing of the psychometric instruments (Buckwalter et al., 1997; Pringle Specht et al., 2000; Pringle Specht et al., 2005). In parallel, qualitative analysis explored further issues identified by family members of SCU residents. The research-based FIC protocol was then more clearly defined to support the instruments and encourage ownership by residential facility staff (Maas et al., 2001; Maas et al., 2000). With the development of the intervention, its impact and identification of outcomes, it became clearer that leadership provided by nursing staff was integral to its success (Gaugler, 2005a; Maas, Kelley, Park, & Specht, 2002; Maas et al., 2004; Maas et al., 2000).

Maas et al. have also focussed on addressing the needs of staff in their role as the primary point of contact with families. Their research demonstrated that if nurses and caregiving staff are to provide the best care to people with dementia and their families then they require education in both role bargaining and partnership negotiation as well as psychological support (Maas et al., 1991; Maas, Buckwalter et al., 1994; Mobily et al., 1992; Pringle Specht et al., 2005). Such education was seen to allow staff to become the liaison point for more meaningful family involvement that is legitimised by the negotiation process and supported by senior management staff (Pringle Specht et al., 2005). Subsequent FIC studies have focussed on the need for health

professionals and managers to understand more about family perceptions of care so that individual adjustments in residential care can occur with as little distress as possible (Buckwalter et al., 1997; Maas et al., 2004; Maas et al., 2001; Pringle Specht et al., 2005) . A summary of the Maas et al. study and partial replications is presented in Table 2.3.

Table 2-3: Summary of Maas et al. Study and Partial Replications

<i>Study</i>	<i>Description</i>	<i>Instruments Used</i>
Maas et al. Study Family Role Trials Family Involvement in Care (FIC) (Maas et al., 2000)	Pre-testing of instruments (Family members = 50, Staff members = 50, Patients = 57). A multi-site study that used a quasi-experimental design with non-equivalent groups with repeated pre-test and post-test measures to examine the effects of the FIC intervention on family, staff and resident outcomes in 14 nursing home SCUs (Family members = 185, Staff members = 775, Patients = 164)	1, 2, 3, 4, 5, 6
Korean Study Korean and US family and staff Caregivers' Perceptions of Care in Dementia Care Units (Park, 2001)	Partial replication of Family Involvement in Care study with patients, families and staff in Korean nursing homes (Family members = 94, Staff members = 112, Patients = 94) – Cross sectional	1, 2, 3, 4, 5, 6, 7
Current Study Examination of Australian family and staff Caregivers' Perceptions of Care in RCFs.	Partial replication of Family Involvement in Care study with families of residents and staff in 2 Australian residential facilities. (Family members = 57, Staff members = 58) - Longitudinal	2, 3, 5, 6, 7

1. *Functional Abilities Checklist (FAC)*
3. *Family Perceptions of Care Role (FPCR)*
5. *Caregivers Stress Inventory (CSI)*
7. *Attitudes Towards Family Checklist (AFC)*

2. *Family Perceptions of Care Tool (FPCT)*
4. *General Job Satisfaction (JGS)*
6. *Staff Perceptions of Caregiving Role (SPCR)*

FIC Theoretical Framework

The essence of the FIC intervention framework is negotiation, clarification, and establishment of mutually satisfactory role expectations for informal and formal caregivers, assisting them through role and environmental transitions to achieve individualised care for the person with dementia. The theories of person-environment fit and interaction (Kahana, 1975; Powell Lawton, 1975) and role theory (Hardy & Conway, 1988) provide the basis for the intervention framework. Person-environment fit provides the basis for proposing that admission to residential care changes the status of both family and staff caregivers, resulting in stress (Powell Lawton, 1989; Schwarz, 2003). Role theory focuses on the interface of individual caregivers' roles as an important aspect of person-environment fit.

Overview – Person-Environment Fit and Interaction Theory

This theory, first developed by Lewin in 1951, defined the environment as a source of tension, force and need (Hardy & Hardy, 1988). In gerontology research a major tenet of person-environment psychology has been the issue of change and changing environments as a source of stress and a salient influence on individual well-being. (Kahana, 1975; Parr, 1980; Powell Lawton & Rubinstein, 2000; Walsh, Craik, & Price, 2000). The term 'stress' in this instance relates to the imbalance between the demands of the environment and the ability or capacity of the individual to cope with those demands (Maas et al., 2001; Pringle Specht et al., 2005). Powell Lawton's model of person-environment fit and interaction, first developed in 1989, proposed that "a match between personal competence and environmental demand is likely to result in favourable behaviour and affect outcomes" (Walsh et al., 2000, p 298). Powell Lawton's research evolved in the US in response to an identified need for modified living arrangements for persons with dementia which would reduce physical environmental barriers and improve behaviour and functionality. Person-environment fit and interaction are conceptualised along the trajectory of changes over time for the person with dementia, family and staff caregivers.

The theory firstly forms a basis for understanding the changing roles of family caregivers as the person with dementia becomes increasingly dependent in all areas of care. Furthermore, when the person with dementia is admitted to residential care, the

role of family caregivers changes from one of primary caregiver to outsider in a new environment where staff assume the primary caregiving role (Specht et al., 2000). From a sociological perspective the person-environment model provides a framework for family caregivers to adapt their role from complete responsibility for all aspects of caregiving to a focus on ensuring quality of life for their relative and an interpersonal role with staff. The framework assists in understanding the importance of the dynamic interaction of family members and staff as a means to re-negotiate changing roles with the person with dementia in what is now their home environment (Cheston & Bender, 1999; Maas, Swanson et al., 1994). The FIC research has identified that as family caregivers negotiate their new roles with staff, stress resulting from the required role changes involving loss, guilt, obligations to provide care and conflicts with staff, should be reduced as their perceptions of the quality of care received by their relative improves (Maas et al., 2000). The framework also helps to guide staff in developing their own roles when suggesting nursing interventions, and to relieve stress and increase positive attitudes towards families as new role expectations and outcomes are clarified. It is predicted that as the partnerships with families develop, staff should also experience relief from task burden and role inadequacy, particularly those who have limited knowledge in caring for the person with dementia and inadequate interpersonal skills when interacting with families (Maas et al., 2000).

In the US, as SCUs were established in residential dementia care, person-environment fit provided solid underpinnings for measuring the trajectory of changes in the role of family and staff caregivers after the person with dementia enters residential care (Maas et al., 2000). As discussed previously, from the outset the FIC intervention was rigorously developed by the Maas et al. researchers in an attempt to provide appropriate scales that measured subjective caregiver well being, and could differentiate treatment effect from random change (Herzog, 1989; Lebowitz, 1989). Recent research supports Powell Lawton's argument that the three characteristics of the model - the person, the environment, and the person-environment fit - are each important predictors of psychological well-being and resident, or client, satisfaction (Kahana, Lovegreen, Kahana, & Kahana, 2003). Alternatively, when environmental demands are too high or too low for the individual, unfavourable behaviour and negative outcomes in relation to stress are more likely (Brush & Calkins, 2008; Goodall, 2006; Walsh et al., 2000). The person-environment fit framework therefore

provides a basis for the measurement of satisfaction, which reflects congruence with care, and dissatisfaction, defined as the “manifestation of stress in response to the discrepancies between reality and expectations” (Maas, Buckwalter et al., 1994, p. 23).

Such a discrepancy between expectations and reality may have already developed prior to admission, as the person with dementia increasingly requires more care than the family caregiver is able to provide. It was established in the Maas et al. study that, as with staff, the role insufficiency felt by families during this time may derive from their lack of knowledge about dementia care and lack of access to service support and resources. An objective of the Maas et al. research, therefore, was to establish a measurement framework which could identify changes in knowledge, stress and satisfaction measures for both family and staff caregivers within the formal care environment. As a consequence, role theory was also used as a basis of measurement to identify the benefits to caregivers of changes in role expectations over time.

Overview – Role Theory

The concept of role theory was first developed by behavioural scientists in the 1930’s. In an effort to clearly explain its origins, Biddle and Thomas (1966) described role theory as a domain of study specifically relating to variances in human behaviour as a result of immediate or past external influences. Another major premise of role theory is that social behaviour is a function of the organisation of which people are members (Biddle & Thomas, 1966). In the FIC study the role theory framework provides the opportunity to focus on exploring the organisational influences of role conflict and its consequences (Calkin, 1988). The ‘fit’ between staff and health care organisations typically can be described as both turbulent and complex, made more so by increasing demands for service change and further education (Calkin, 1988). For the purposes of the FIC study, role theory provided the framework for examining the salient features of role conflict (role strain and role stress) and the influences of the aged care organisational culture on family and staff caregivers’ social behaviour and inappropriate role expectations (George, 1980).

In the social and organisational construct of residential dementia care a tension exists between environmental forces that act to ‘produce’ behaviour and social constructs

that demand maintenance and evolution of role performance. Lack of achievement may result in role strain and conflict, both for families and staff (Hardy & Conway, 1988). For staff caregivers, their caregiving role may not necessarily be seen as positive or inclusive by family caregivers, creating conflict situations and feelings of guilt, embarrassment, anger/resentment and anxiety/depression for both parties (Maas et al., 2001). In the context of dementia care therefore, role theory helps to make sense of the importance of understanding ‘personhood’ in the social context of residential care, not only for families and residents, but also for staff.

It was identified in the literature that, as with families, staff stress may also be influenced by the burdens and responsibilities of caring for the slowly deteriorating person with dementia, including role conflict, overload, ambiguity and changes in role expectations (Maas et al., 2001). The Maas et al. study identified that staff stress levels may present as psychological dimensions of task burden, role inadequacy, dominance and exclusion (Maas et al., 2004). Role theory argues that it is fundamental to human nature to be socially accepted and maintained, if not evolved, our status when interacting with others (Hardy & Conway, 1988; Walsh et al., 2000). This premise acts in contradiction to the deteriorating nature of the cognitive decline of dementia and the difficulties with maintaining social roles. Lack of orientation during admission of the person with dementia to residential care and lack of interaction between staff and families may also undermine the roles assumed by all parties, resulting in role conflict. As a consequence, if staff members claim the person with dementia as ‘their’ resident without positively negotiating the caregiving role with families, an adversarial relationship may continue to develop. Alternatively, conflicts may arise if families over- or under-estimate their roles within the new environment, or when overlaps with staff roles and responsibilities occur.

FIC Intervention – Critique

In summary, the Maas et al. studies have been instrumental in improving dementia-specific environments in residential care and improving family caregiver satisfaction by promoting their involvement in care. So too have staff attitudes improved as a result of the education intervention and improved relationships with families.

This literature review has identified the limitations in utilising one cross-sectional or qualitative research method in isolation to evaluate the success of a program that promotes family involvement in residential care (Haesler et al., 2006). The FIC intervention protocol was seen to provide a theoretical and conceptual framework which is central to the intervention constructs; it has been iteratively developed from descriptive research and is specifically designed for the target population in the residential care setting. A number of strengths were therefore considered in choosing to use the FIC design as the framework for implementing and evaluating an intervention in the context of family involvement in residential dementia care.

Firstly, the partnership model is based on improving relationships between family and staff caregivers to ultimately improve care of the person with dementia within the residential care environment. Secondly, the education and partnership intervention has been developed as an evidence-based protocol for residential care. Thirdly, a longitudinal design enables the opportunity for full examination of the “treatment effect” of the intervention and the dynamics of family-staff relationships. Fourthly, there is the opportunity to converge qualitative and quantitative findings through a consistent framework related to the dynamic relationship between staff and family caregivers of the person with dementia.

The limitations of utilising the FIC design in the Australian context were considered to be the different structure of SCUs in the US, which impacts on staffing ratios and organisational culture. It was decided therefore that this study would be a partial replication of the Maas et al. research, and measurement of changes for the person with dementia would not be taken into account.

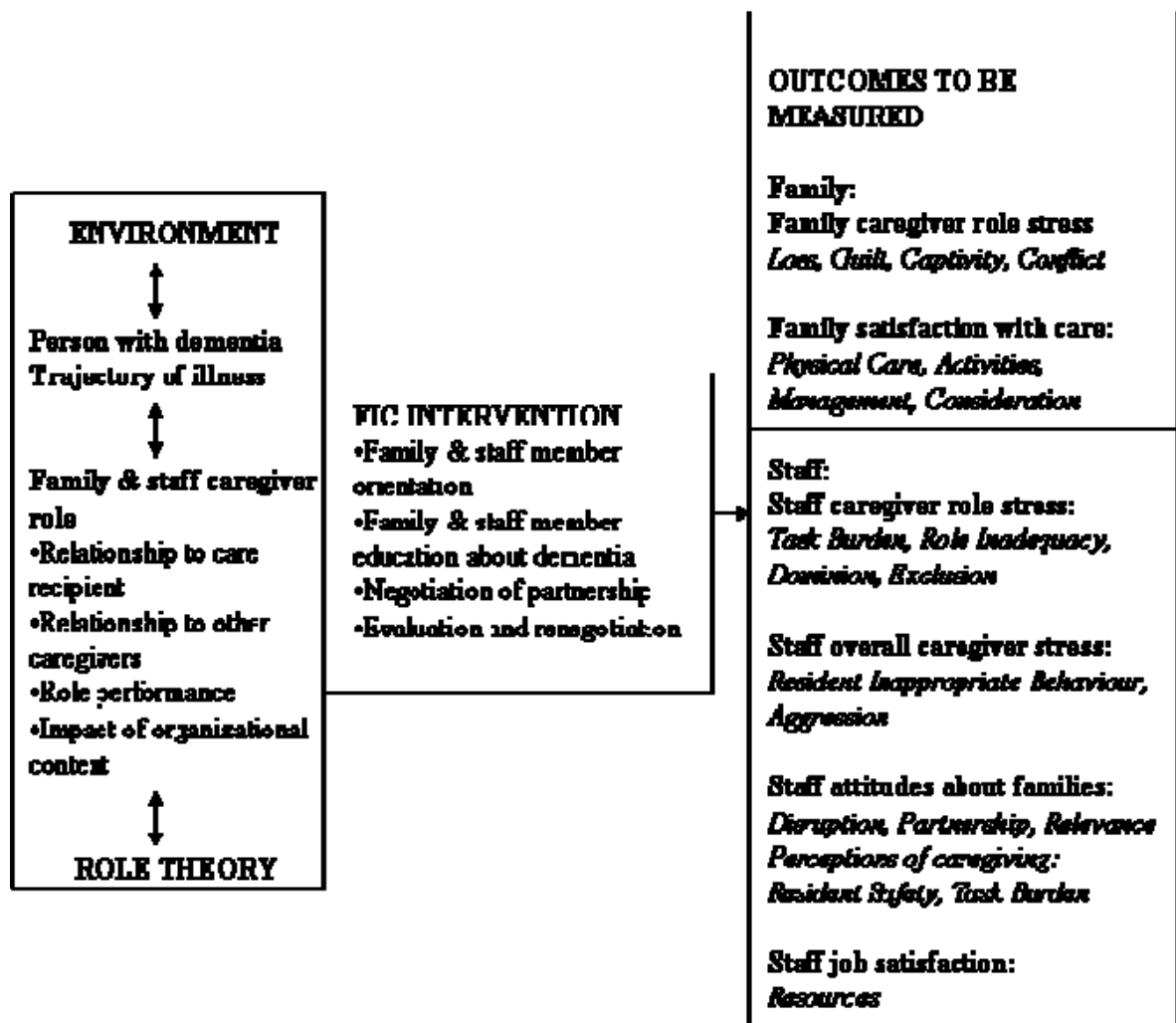
Theoretical Framework of the FIC and Outcomes

The aim of the FIC education intervention and family-staff partnership model is to relieve the stress of caregiving for families by reducing their feelings of loss, guilt, obligations to provide care and conflicts with staff. Likewise, the partnership aims to relieve the stress of staff caregiver task burden and role inadequacy by improving knowledge and resources to assist them in dealing with both the resident with dementia and interactions with family caregivers. The beneficial outcomes from the partnership for staff are identified as improved attitudes towards families and

improved job satisfaction as a result of reduced conflict with families in caring for the person with dementia (Maas et al., 2000). Family beneficial outcomes are identified as reduced role stress and improved satisfaction with care. Furthermore it is possible to unbundle the intervention and identify the rationale of each component, as identified in the protocol.

In summary, the FIC theoretical framework drives the expectation that the intervention will improve family and staff caregiving roles and relationships, thus improving caregiver stress and satisfaction outcomes (Maas et al., 2004; Pringle Specht et al., 2005). Figure 2.1 presents an overview of the FIC intervention framework and outcomes.

Figure 2-1: Theoretical Framework of the FIC Intervention and Outcomes



Research Questions

This study sought to examine the success of the FIC intervention for family and staff caregivers of residents with dementia. The research questions that guided the quantitative phase of the study were:

Does the FIC model of care, based on the theoretical models of person-environment fit and role theory:

1. Improve knowledge of dementia for family and staff caregivers?
2. Improve satisfaction and reduce stress for family caregivers?
3. Improve job satisfaction and reduce work stress for staff caregivers?

Based on the research questions the research hypotheses tested were:

- H1. There will be an improvement in family caregiver knowledge, reduced stress and improved satisfaction for those who participate in the FIC intervention compared to those who do not.
- H2. There will be an improvement in staff caregiver knowledge, reduced stress, improved attitudes towards families and improved job satisfaction for those who participate in the FIC intervention compared to those who do not.

Summary and Conclusions

The literature review firstly examines the complex and multidimensional needs of family caregivers during and after the transition of their relative with dementia to residential care. Secondly, the importance of family involvement in care is discussed in the context of person-centred care and the development of family-staff partnerships. Thirdly, the effects of dementia caregiving on staff are examined, with particular emphasis on the need for improving education programs in dementia care. Fourthly, the FIC education intervention and partnership model, its development, theoretical framework and strengths and weaknesses are critiqued. Finally, the FIC theoretical framework and an overview of the FIC model of care are presented.

Chapter Three presents a detailed description of the FIC research method, design, samples, measurement tools and ethical considerations used in the current study.

CHAPTER 3

METHOD

Introduction

This chapter provides an outline of the overall methodology of the study, which sought to implement and evaluate the FIC intervention in two RCFs in Brisbane, Australia. The literature in Chapter Two highlighted the limited empirical research in Australia that examines the extent of family involvement in residential dementia care. Overseas research has emphasised the importance of education, communication and negotiation skills and the development of productive relationships between family and staff in promoting family involvement in dementia care. A common theme of the studies is the ongoing need to build on evidence-based research using clear theoretical models and empirically-validated treatments to measure caregiver outcomes. The controlled trial design of this partial replication study was considered appropriate to minimise the effect of extraneous factors and allow conclusions about the effectiveness of the intervention to be made (Zarit & Femia, 2008). The mixed method, sequential two-phase study design also aimed to integrate family caregiver qualitative and quantitative findings so that the research questions may be answered in the Australian context.

Firstly, the research design and method are discussed, including a description of the study settings and family and caregiver samples. Secondly, an overview is given of the FIC intervention design, treatment effect and outcome measures. Thirdly, the FIC family and staff caregiver instruments are presented with particular emphasis on linking the theoretical framework discussed in Chapter Two to the outcome measures. Fourthly, a description is given of the FIC instruments' reliability and validity, qualitative and quantitative data collection procedures, research rigour and ethical considerations. Finally, the research questions, statistical procedures and study limitations are discussed.

Research Design and Method

This PhD study was a partial replication of the Maas et al. study in Australia. The Maas et al. research identified that documentation of measures and data collection from people with dementia were constantly problematic, mainly due to low compliance from staff (Maas et al., 2000). Consequently this study was interested only in family and staff outcomes and it was decided not to take resident measures into account in the intervention. This study utilised a controlled trial design with randomised allocation of two residential sites but not the sample (Maas, Buckwalter, Reed, & Specht, 1998). Repeated pre-test and post-test measures were used with the standardised psychometric instruments tested and validated in the Maas et al. research (Maas et al., 2004; Maas et al., 2000; Pringle Specht et al., 2005). The self administered questionnaires focused on measuring family and staff caregivers' perceptions of care and caregiving roles for persons with dementia in residential care. Pre-intervention qualitative interviews were used to gain in-depth information about family caregivers' experiences both before and following placement of their relative in long-term care. The post-intervention qualitative interviews supported the quantitative findings by providing clarification of family caregivers' perceptions of the success of the intervention (Creswell, Clark, Gutmann, & et al, 2003).

This study is described as mixed method with a sequential two-phase design (Creswell et al., 2003; Tashakkori & Teddlie, 1998). Mixed method designs are characterised by methodological integration, where no method is linked to a particular paradigm of inquiry (Tashakkori & Teddlie, 1998). The emergence of mixed methods has occurred as a result of the 'paradigm wars', which reflected the debate and ultimate evolution of 'pragmatism' as the philosophical underpinning for mixed methods research (Creswell & Plano Clark, 2007; Tashakkori & Teddlie, 1998). The advantage of mixed methods is that it allows for measurement of trends and outcomes, as well as meaning and context (Creswell & Plano Clark, 2007). The focus then turns to integrating the different methods and determining the sequence of the methods to address the research question. In line with the call by health practitioners and policy makers for increased sophistication in the provision of new evidence-based knowledge, each component of mixed method data can then improve

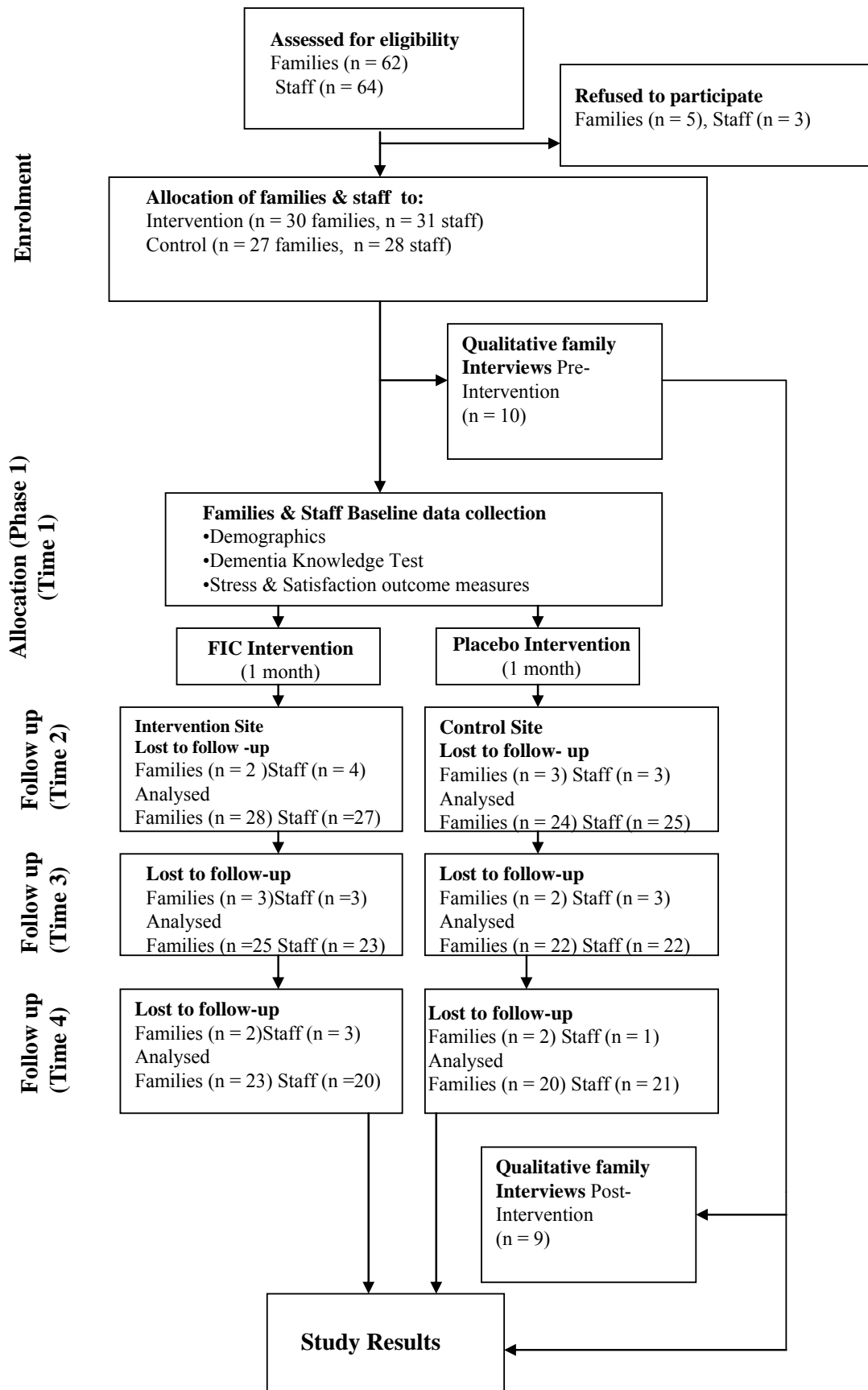
knowledge from a number of perspectives and each phase can be presented as a discrete study.

The qualitative phases of this study were crucial to addressing the research problem by providing new knowledge about family experiences of residential dementia care in the Australian context. The first qualitative phase described the changes in the environment in which family caregivers found themselves during transition to residential care. The quantitative data were analysed in two ways. Firstly, differences between the control and intervention sites were analysed to measure the differences in effect between the FIC and 'placebo' interventions. Secondly, differences in the intervention 'treatment' effect between the short term and long term were analysed. The second qualitative phase described family caregiver views of the benefits of the partnership intervention and how they perceived its potential for success.

Depending on the question, there is a general acceptance that the mixed method mode of inquiry provides a better understanding of the research problem than one method of inquiry alone. Because of the level of complexity inherent in this study, and the interdisciplinary nature of the research, this method of inquiry allowed for expanded understanding of the research problem (Creswell, 2009). Moreover, given the problems associated with the heterogeneous nature of the family and staff caregiver samples, and the difficulties with recruiting and retaining large numbers of family or staff participants, it was important that the quantitative data could be examined in the context of the qualitative findings.

Hence the qualitative and quantitative phases of the study are distinct, but both assist in providing credence to measurement of the value of the intervention (Mittelman, 2008). The post-intervention interviews assisted in providing an interpretive context to the quantitative outcomes. Both the qualitative phases were used to address the research questions regarding family and staff caregiver well-being, as identified in Chapter Two (Tashakkori & Teddlie, 1998). Moreover, both qualitative phases of the study were linked to each other in a developmental manner, such that the results from one phase informed the use of the next phase. The following diagram summarises the study design and method, and flow of study participants through each study phase (Altman et al., 2001).

Figure 3-1: Study Design & Method



Study Settings

Family and staff participants were recruited from two RCFs in Brisbane, Queensland. The settings were chosen for their similarity in terms of business ownership, staff mix, resident profile, caregiver demographics and the care environment. Each facility included low care predominantly in the hostel, high care predominantly in the nursing home, and a dementia specific Special Care Unit (SCU). On a practical level implementing the intervention and the 'placebo' at different, geographically distant sites lessened the risk of contamination of participants (Blackwood, 2006; Maas et al., 2002). Consequently, as with the Maas et al. study, one site in the pair was randomly assigned to be the experimental site and the other to be the control site. A coin toss decided which site would be the control site and the intervention site. However, the major limitation of this approach is the increased risk of identifying a 'placebo effect' at the control site as both staff and family participants experience benefits from the dementia education component of the intervention.

Study Samples

Family Caregivers

As identified in Chapter One, associated with the increasing prevalence of persons with dementia in RCFs is the number of family caregivers who have been impacted by the burden of dementia, particularly those defined as 'primary caregivers'.

Primary family caregivers were defined as persons who took the chief responsibility for caregiving for the person with dementia, both at home and following admission to the RCF. In this study, the role of primary caregiver was identified both by senior management at each facility and through self identification by the family caregiver.

Inclusion criteria for participation by family caregivers were: 1) age 18 years or older; 2) evidence of monthly contact with their relative with dementia; and 3) agreement to participate in the study throughout the nine month study period.

Residents

The inclusion criteria for residents with dementia whose families were considered for the study were: 1) a medical diagnosis of irreversible dementia confirmed by neuropsychological evaluation, documentation in the care plan and verification from facility management; 2) exclusion of all other specific causes of reversible dementia; 3) older than sixty five years of age; and 4) no history or current diagnosis of a major psychiatric illness.

Staff Caregivers

As highlighted in Chapter One the population of Registered Nurses working as staff members in residential aged care is limited and diminishing. Of those remaining a high percentage choose to work part-time. Taking into account these limitations to staff participation it was decided that the major inclusion criterion for staff caregivers would be to work a minimum of eight hours per week. This requirement ensured that staff would not only be available to maintain the minimum monthly contact with family caregivers but also would more likely be available to participate in the study for the nine month period. Other inclusion criteria required to fulfil the role of primary staff caregiver were: 1) a Registered Nurse (RN), Enrolled Endorsed Nurse (EEN) or Diversional Therapist (DT) qualification; or 2) a Personal Care Worker (PCW) with a minimum Certificate III qualification and minimum three years experience; and 3) a minimum three years experience at the RCF site.

In order to achieve the numbers required for the study to achieve sufficient power of 0.80 (alpha level of 0.05), staff and family participants (60 family members and 60 staff members) were drawn from all areas of each RCF including the SCU, high care and low care. Information sessions were conducted for staff in each section of the facility by the Researcher and Senior Management, with a focus on promoting the benefits of participation in the study for staff and family caregivers of the person with dementia. Interested participants were informed that the time they spent completing the education sessions would be equivalent paid time and part of their annual training program.

Assignment of Staff to Family Caregivers

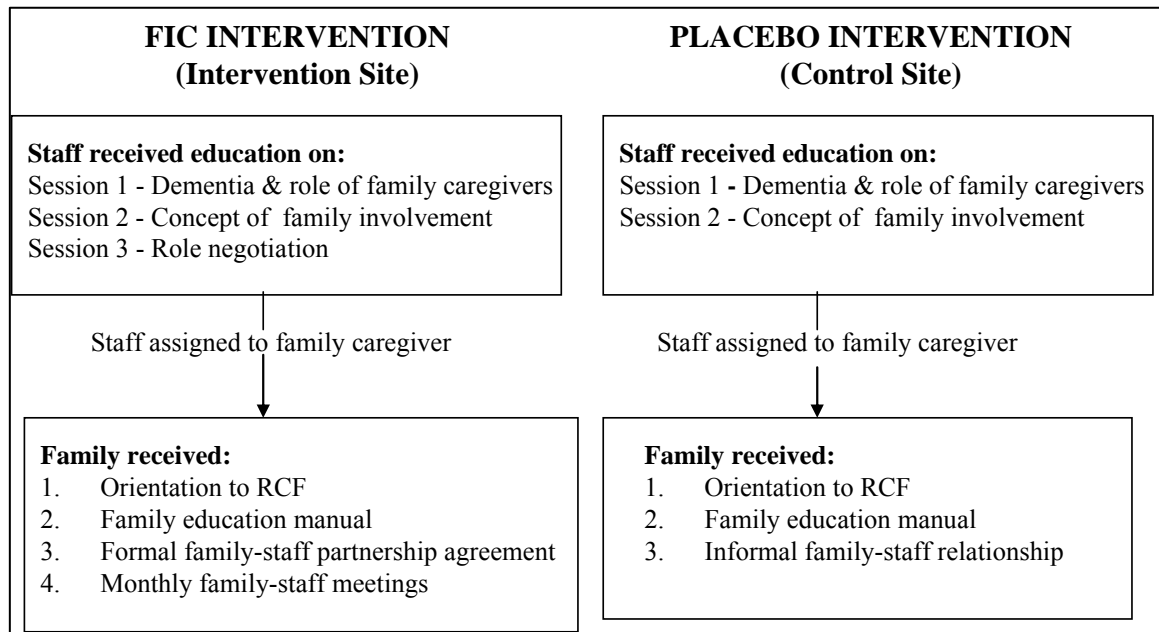
The senior management at each RCF were responsible for non-random assignment of staff to family caregivers. This process ensured that staff with the appropriate skills, experience and knowledge of the individual person with dementia would be assigned to the primary family caregiver. It was also important from a coordination perspective that, where possible, staff who worked predominantly in specific sections of the RCF were assigned to the family caregiver of the person with dementia who also resided in that section. This increased the likelihood of staff and family caregivers making contact on a regular basis, an important requirement of the FIC intervention.

FIC Education Intervention Design

The FIC intervention aims to promote and improve family and staff well-being through the establishment of therapeutic family-staff partnerships, that focus on caregiving for the person with dementia. It was designed to achieve this through family and staff education and a contractual partnership between each family-staff relationship. The intervention builds on the psychological theories of person-environment fit and interaction and role theory, which are discussed in Chapter Two. The major quantitative measurement parameters of the intervention derived from the theory are associated with family and staff caregiver knowledge, stress and satisfaction. The effects of the partnership intervention are measured by comparison with the control or 'placebo' group, who receive the 'placebo' intervention.

The major aspects of the intervention for both family and staff caregivers were education, linking with a caregiver partner and, at the intervention site, formal negotiation of care. For family caregivers the education was comprised of the Family Education Resource Manual (see Appendix E1 for Summary of Contents), supported by the FIC brochure. The Family Education Resource Manual used in this study was modified from the Maas et al. version to fit more specifically with the dementia care services offered at the RCFs in Brisbane, Australia. A comparison between the FIC intervention and the 'placebo' intervention are presented in Figure 3.2 .

Figure 3-2: FIC & Placebo Intervention



In summary, staff participants at the intervention site received training in all four stages of the FIC intervention protocol in three training sessions. The control group completed only three stages of the protocol in two training sessions. The Researchers, who provided the education, demonstrated how to formalise the FIC Family-Staff Partnership Agreement through negotiation of care, with particular emphasis on the theoretical underpinnings of the FIC intervention protocol, described in the following section.

The FIC Education Intervention Protocol

As identified in Chapter Two the FIC intervention protocol was derived and refined from the environmental psychologist Powell Lawton’s earlier work. His aim in developing the physical design of residential settings, based on person-environment fit theory, was to provide an environment which was more appropriate for the needs of people with dementia. The major principles Powell Lawton identified were orientation, negotiability, personalization or social interaction and safety (Caulkins, 2003). These key principles contributed not only to the evolving physical design of

residential settings, but also to the evolution of dementia caregiving roles, both for family and staff. Hence person-environment fit and role theory provided the framework for the development of the four step FIC education intervention framework, and were replicated in this study as follows:

1. Orientation of an identified primary family caregiver (and other family caregivers if they wish to participate) to the facility and the proposed partnership role. This should occur no matter the length of time that the resident has been in the facility.
2. Education of family members for involvement of care. The family caregiver received a copy of the Family Education Resource Manual. When the primary nurse was assigned to the family member (after the collection of baseline data), he/she discussed the therapeutic activities and personal care described in the manual, and how they may be considered on an individual basis.
3. Completion of the Family-Staff Partnership Agreement (see Appendix F1). Agreements were negotiated at the intervention site between each family and staff caregiver participant. Activities were classified in the agreement as to the number of contacts, intensity of participation, contact length, and frequency of contact. Activities family members agreed to undertake with staff ranged from provision of personal information about the resident to active participation in care or assistance with psychosocial activities. The aim was for family caregivers to be contacted monthly by the relevant staff member to discuss and change the activities or terms of the agreement if necessary.
4. Staff education sessions. Staff at both sites received education in two sessions, totalling six hours of training. Only assigned staff participants at the intervention site attended the third session (see Figure 3.2).

The Family-Staff Partnership Agreement

Central to the intervention was the family/staff meeting for establishing the extent of family caregiver involvement. Firstly, to begin negotiating the partnership agreement, each family and staff caregiver began by discussing goals and approaches to care. Secondly, they discussed the individual activities each would perform in order to

achieve agreed upon realistic goals of care. It was important for staff to make it clear to family caregivers that the aim of the process was to enable them to partake in activities they wanted to do, not as a requirement from staff. The activities were identified in the Family-Staff Partnership Agreement, with the option to document additional requirements. The number of contacts, intensity of participation, contact length and frequency of contact were agreed to and documented on this form. Activities agreed to by family caregivers ranged from simple provision of information about the resident to active participation in physical care and psychosocial activities.

Family Caregiver Education

The staff member assigned to the family caregiver, together with the researcher, were responsible for providing the Family Education Resource Manual to the family caregiver. The Resource Manual was developed specifically to increase knowledge of dementia care for families whose relative is in residential dementia care. Accordingly each family caregiver participating in the study received a copy. The information in the manual aimed to provide them with information about dementia, and to offer personalised therapeutic and diversional activities for their relative. Selected categories of these activities and interventions were: behaviour management, person-environment fit, exercise, nutrition, medication management, music therapy, non-restraint strategies, personal care and therapeutic recreation. The brochure, which promoted the manual, provided a summary of the FIC intervention and its benefits. The family caregiver information was also available for staff so that, if necessary, they could provide additional individual instruction to family caregivers as to how they could increase their involvement in care of the relative within the facility. This matter was particularly important for spouse caregivers who were more likely to need support from staff in absorbing the content of the manual.

Staff Education

As discussed, the aim of the sessions at each site was to emphasise the rationale for the intervention, and provide staff participants with the skills required to implement either the placebo or the partnership intervention. Each session was of two hours duration. The first session presented information about dementia. The second session discussed the problems faced by family members of residents in long-term residential care. All staff participants involved in the study were required to attend the first two sessions. The third session provided a framework for staff on how to negotiate with

family caregivers to implement their care role and increase their involvement in care. The content of session three included role negotiation and conflict resolution skills, reinforcement of approaches in the care of the person with dementia, and practice in taking on the new partnership role through discussion and role play experiences. An outline of the staff training program is presented in Appendix D1. If any staff participants were unable to attend the training sessions, arrangements were made by the researcher to provide the training on an individual basis.

The FIC Intervention Treatment Effect

The quantification of the dose of the FIC intervention, as documented on the Family-Staff Partnership Agreement, equalled the sum of values for participation (intensity level), contact length, and frequency for all activities. The minimum therapeutic ‘treatment effect’ of the intervention was defined as *participation in at least one care activity at level one intensity (provision of information for care plan) for at least ten minutes for each contact, and at least monthly* (Maas et al., 2000). Because family members were often involved in a number of activities, only those that were negotiated as part of the agreement were quantified on the form (see Appendix F1) to more accurately reflect the minimum therapeutic dose or treatment effect of the intervention. The dose of the intervention is consistent with the theoretical framework, fits with clinical reality and is sufficient to affect outcomes over time (Conn, Rantz, Wipke-Tevis, & Maas, 2001).

Renegotiation of the partnership agreement allowed for its adjustment to the changing condition of the resident and changing ideas from family caregivers about the role they wanted to play. Where possible, monthly sessions were conducted between staff and family caregivers with the aim of re-evaluating and renegotiating the terms of the Family-Staff Partnership Agreement. A summary of the information collected from the agreements at the intervention site about the number of family/staff contacts, intensity of participation, contact length and frequency of contact is presented in Chapter Seven. At the intervention site, ongoing individual support was provided by the researcher to monitor staff compliance with the FIC protocol and use of the agreement. During the nine month period of the intervention the researcher also provided individual staff participants with ongoing education, consultation and role modelling.

The following section discusses the outcome measures used to examine the effects of the FIC intervention on family and staff caregivers.

FIC Outcome Measures

The purpose of the FIC intervention was firstly to improve family and staff caregiver knowledge about dementia and dementia care. Secondly, it aimed to decrease family caregivers' stress from loss of the positive aspects of their relationship with the person with dementia, guilt, captivity (restrictions imposed by the obligations to provide care), and conflict with staff. Thirdly, the intervention aimed to improve family caregiver satisfaction with care of their relative with dementia, whilst also improving staff job satisfaction, increasing positive attitudes about families, and reducing perceived stressors - role inadequacy, task burden, dominion (control of care vis-à-vis family caregivers), and exclusion (resistance to involvement in care from family members). As with the Maas et al. research, the instruments used in this study were assembled into four outcome clusters corresponding to the four aspects of the caregiving role as described in the theoretical framework in Chapter Two. Both the family and staff outcome measures were clustered within matching aspects of the caregiving role, as summarised in Table 3.1 on the following page.

Table 3-1: Outcome Clusters for each aspect of Caregiving Role

Aspect of Caregiving Role	Family Caregiver Outcome Cluster	Staff Caregiver Outcome Cluster
Relationship to care recipient	Emotional reactions to care recipient Loss Captivity Guilt	Emotional reactions to care recipient Inappropriate behaviour Aggression
Relationship to other caregivers	Perceived relationship with staff Conflict Disregard	Perceived relationship with families Dominion Exclusion Disruption Partnership Irrelevance
Adequacy of role performance	Perceptions of care Physical care Activities	Perceptions of caregiving Role inadequacy Task burden Resident harm
Perceived organisational performance	Perceptions of management Management effectiveness	Perceived organisational support Resource (deficiency)

The outcome cluster measures are adopted from the Maas et al. study. In this study it was hypothesised that family caregivers involved in the family-staff partnership intervention would improve their knowledge and experience lower stress and improved satisfaction compared to the control site. In addition it was hypothesised that staff caregivers at the intervention site would report reduced stress, more favourable attitudes about family caregivers and more job satisfaction. The proposed study hypotheses are presented in Chapter Two. The standardised measurement tools chosen from the Maas et al. study to enable testing of the hypotheses are presented in the following section. These same instruments were also used so that cross-cultural comparisons could be made with the Maas et al. findings.

Family Caregiver Instruments

As identified in Chapter Two the FIC instruments have been rigorously developed and tested in a number of research studies in the US as well as in South Korea (see Table 2.3). Except for minor wording changes to accommodate Australian terms, the

instruments, including the Demographic categories, were replicated in this study. Family knowledge of dementia was measured by the Family Knowledge of Dementia Test (FKDT). Family caregiver outcomes were measured by the Family Perceptions of Caregiving Role (FPCR) instrument and the Family Perceptions of Care Tool (FPCT). Table 3.2 below presents an overview of how the outcome cluster measures for each family instrument relate to the theoretical framework.

Table 3-2: Overview of Family Instruments & Theoretical Framework

Family Caregiver Measures	Scale	Measure	Theoretical Framework
Family Knowledge of Dementia Test (FKDT)	True/False	Assess individual level of knowledge families possess about dementia	Etiologic pathology of dementia Signs and symptoms of dementia Treatment and care of persons with dementia
Family Perceptions of Caregiving Role (FPCR)	7 point Likert 4 subscales 61 items	Stress related to person with dementia (<i>Subscales: Guilt, Captivity, Loss, Conflict</i>)	Person-Environment Fit & Role Theory (role conflict)
Family Perceptions of Care Tool (FPCT)	7 point Likert 4 subscales 51 items	Satisfaction with care (<i>Subscales: Physical Care, Activities, Management Effectiveness, Consideration</i>)	Role Theory

Family Demographics

Demographic information was collected from family caregiver participants at the baseline interview. The ‘education’ and ‘occupation’ demographic classifications were modified slightly from US to Australian wording for consistency with demographics collected by the Australian Bureau of Statistics. In all other respects the demographic classifications were replicated so that cross-cultural demographic data comparisons between this study and the Maas et al. study could be made (see Appendix A1).

Family Knowledge of Dementia Test (FKDT)

The FKDT was used pre- and post-intervention to ascertain improvement in knowledge of dementia for families. The topics covered were signs and symptoms of dementia related illnesses, behaviour management and etiologic pathology (see Appendix A2). The FKDT is a 22 item true/false instrument for assessment of family knowledge about dementia. The terminology was changed from ‘Alzheimer’s’ to

'dementia' to more clearly reflect the broad range of dementias. The FKAT was derived from the Knowledge of Alzheimer's Test (KAT). The original KAT contained 20 items and was developed at the Dementia Clinic, Department of Neurology, the University of Iowa Hospitals and Clinics (Maas et al., 2000).

FKDT Reliability and Validity

The original 20 item tool was pre-tested using parallel forms with 20 nursing home staff and produced a reliability coefficient of 0.80. Because high scores were consistently obtained it was concluded that the instrument did not discriminate across knowledge levels, therefore the instrument was revised to include 22 items. The Maas et al. test-retest reliability and internal consistency reliability results are presented in Table 3.3. Content validity was assessed from a review of the literature and by a panel of gerontology nurses who were experts in the care of persons with dementia.

Family Perceptions of Care Tool (FPCT)

The FPCT, originally developed by Mass and Buckwalter in 1990, measures family satisfaction with the care of their relative in residential care. Each of the 51 items in the instrument is measured by a 7-point Likert scale, with 7 indicating highest satisfaction and 1 indicating highest dissatisfaction. Item scores are summated within four subscale scores (see Table 3.2) as well as a total FPCT score. The current version of the FPCT comprises four subscales to measure dimensions of satisfaction with care, defined as: 1) physical care; 2) activities for residents; 3) management effectiveness; and 4) staff consideration for residents and families (Maas et al., 2004). The scales of the FPCT are linked to the theoretical framework through the character of the four aspects of the caregiving role as described in Table 3.1. In this current study family members typically took between 20 and 30 minutes to complete the 51 items in this instrument. For some older spouses of people with dementia it took longer and at times they required assistance from the researcher (see Appendix A4).

FPCT Reliability and Validity

During development of Version 1 of the FPCT, test-retest reliabilities for the subscales ranged from 0.78 to 0.90 ($p < 0.05$), based on data from 15 family caregivers of persons with dementia, within an interval of 10 days. Similar reliabilities were achieved for Version 2 (Maas et al., 2000). For Version 2 (Study 3),

baseline internal consistency reliability data were 0.97 for physical care, 0.87 for activities, 0.88 for management effectiveness and 0.85 for consideration (Maas et al., 2000). The Cronbach's alphas for Study 4 conducted with Korean family caregivers were 0.83 for physical care, 0.81 for activities, 0.60 for management effectiveness, 0.70 for consideration and 0.94 for the FPCT total score (Butcher et al., 2001). In the current study Cronbach's alphas were 0.53 for physical care, 0.84 for activities, 0.61 for management effectiveness, 0.64 for consideration and 0.94 for the FPCT total score. In accordance with previous studies there was greater variance in item scores that referred to the care family caregivers would like their relative to receive if there were more resources and staff available, that is management effectiveness and consideration.

Content validity was assessed by a panel of gerontology nurses and social workers, who reviewed and revised the instrument. Item selection was based on a review of the limited literature about family caregivers of residents with dementia and was derived from the theoretical framework. When this instrument was developed only instruments that measured family perceptions of care of people with dementia in the community were available, thus no criterion measure was found for further validation.

Family Perceptions of Caregiving Role (FPCR)

The FPCR is a 61-item self-report tool that measures a number of dimensions of family caregiver stress associated with their relative's admission to residential care. This tool was also developed by Maas and Buckwalter (1990), with some items adapted from the Burden Inventory (Zarit, Todd, & Zarit, 1986). Items related to grief, role deprivation and role capacity were modified from measures developed by Pearlin, Mullan, Semple, and Skaff (1990). The content of the instrument originated from the theoretical frameworks of Person-Environment Fit and Interaction (Kahana, 1975) and Role Theory (Hardy & Conway, 1988). Items are rated on a 7-point Likert scale (1 = strongly disagree to 7 = strongly agree). Originally the instrument was designed to measure stress and burden from the caregiver role (see Appendix A3).

As the instrument developed, four dimensions of stress related to the caregiver role were identified. These were defined as: 1) loss of aspects of the relationship with the relative with dementia; 2) guilt from perceived failure in caregiving; 3) captivity

resulting from obligations of caregiving; and 4) conflict with staff related to caregiving. Once again in the current study it typically took family members between 20 and 30 minutes to complete this questionnaire. The scales of the FPCR are linked to the theoretical framework through the character of the four aspects of the caregiving role, as described in Figure 2.1.

FPCR Reliability and Validity

Pre-testing of 50 family members in Study 3 revealed Cronbach's alphas of 0.93 for total stress, 0.93 for caregiving role stress, 0.94 for burden and 0.87 for loss (reference). The Cronbach's alpha for Study 4 were 0.83 for loss, 0.74 for guilt, 0.80 for captivity, 0.60 for conflict and 0.94 for the total scale (Butcher et al., 2001). In the current study Cronbach's alphas were 0.76 for loss, 0.75 for guilt, 0.78 for captivity, 0.81 for conflict and 0.94 for the total scale.

A summary of the Maas et al. family instrument test-retest reliability and internal consistency reliability results as the instruments were modified are presented in Table 3.3.

Table 3-3: Summary of Family Instrument Modification

Family Instrument	Instrument Subscale	Study 3* Internal Consistency Reliability 2000(N=20)	Test-Retest Reliability 2000 (N=12) (1 month)	Study 4* Internal Consistency Reliability 2001(N=50)
FKDT				
<u>Version 1 (20 items)</u>	Total	.80		
	Total		.82	.61
<u>Version 2 (22 items)</u>				
Family Instrument	Instrument Subscale	Study 3* Internal Consistency Reliability 2000(N=50)	Test-Retest Reliability 2000 (N=15) (3 weeks)	Study 4* Internal Consistency Reliability 2001(N=94)
FPCR				
<u>Version 1</u>	Stress	.93	.85 - .89	
	Burden	.94	.92 - .86	
	Loss	.87	.83 - .90	
<u>Version 2</u>	Guilt	.70		.93
	Captivity	.81	Test –	.81
	Loss	.73	Retest**	.60
	Conflict	.84	.70 (p<.001)	.70
FPCT				
<u>Version 1</u>	<u>Satisfaction with:</u>			
	Environment	.88		
	Nursing care	.94		
	Relationships	.85		
<u>Version 2</u>	Overall care	.87		
	Physical care	.97		.74
	Activities	.87		.80
	Management effectiveness	.88		.83
	Staff consideration (regard)	.85		.60

* Cronbach's Alpha

** Pearson's Correlation

The following section presents the standardised staff measurement tools chosen from the Maas et al. study to enable testing of the hypotheses and cross-cultural comparisons of the data.

Staff Caregiver Instruments

Staff Demographics

Staff caregiver demographic information was collected from participants at the baseline observation period. As with the family data, staff demographic education, occupation and highest qualification classifications were modified slightly from the US to Australian wording for consistency with demographics collected by the Australian Bureau of Statistics. In all other respects the demographic classifications were replicated so that cross cultural data comparisons between this study and the Maas et al. study could be made (see Appendix B1).

Staff knowledge of dementia was assessed using the Staff Knowledge of Dementia Test (SKDT). Staff member outcomes were measured by the Staff Perceptions of Caregiving Role (SPCR), the Caregiver Stress Inventory (CSI) and the Attitudes towards Family Checklist (AFC). Table 3.4 below presents an overview of the outcome cluster measures for each staff instrument, and how they relate to the theoretical framework.

Table 3-4: Overview of Staff Instruments

Staff Caregiver Measures	Scale	Measure	Relationship to Theoretical Framework
Knowledge of Dementia Test	True/False	Assess individual staff caregiver level of knowledge	Etiologic pathology, signs and symptoms and care of persons with dementia
Staff Perceptions of Caregiving Role (SPCR)	7 point Likert 4 subscales 58 items	Stress (<i>Subscales: Dominion, Exclusion, Task Burden, Role Inadequacy</i>)	Role Theory (role strain, role overload, role conflict)
Caregiver Stress Inventory (CSI)	7 point Likert 4 subscales 43 items	Stress related to person with dementia (<i>Subscales: Inappropriate Behaviour, Aggression, Resident Safety, Resources</i>)	Person/Environment Fit Burden Inventory
Attitudes about Family Checklist (AFC)	7 point Likert 3 subscales 16 items	Attitudes (<i>Subscales: Disruption, Partnership, Relevance</i>)	Role Theory

Staff Knowledge of Dementia Test (SKDT)

As with the FKDT, the SKDT is a replication of the original KAT (Maas & Buckwalter, 1990), with the only change in terminology from Alzheimer's disease to

dementia. The FKDT is a 33 item true/false instrument used to assess the information staff possess about dementia (see Appendix B2). The questions address three areas of knowledge: 1) the etiologic pathology of dementia; 2) signs and symptoms of dementia; and 3) the treatment and care of residents with dementia. The total score is determined by the number of correct answers. Content validity was assessed from a review of the literature and by a panel of gerontology nurses. The original 20-item tool was pre-tested using parallel forms with 20 nursing home staff and produced a reliability coefficient of 0.80. The summary of staff instrument reliabilities is presented in Table 3.5.

Staff Perceptions of Caregiving Role (SPCR)

The SPCR is a 58-item self-reported instrument developed by Maas and Buckwalter (1990) that measures multiple dimensions of staff perceptions of family and staff caregiving roles as sources of stress (see Appendix B3). A number of the items of the SPCR are analogous to items in the FPCR instrument. Various aspects of the staff caregiver role are examined, as well as interactions and negotiations with family members. Some items were adapted from the Burden Inventory (Zarit et al., 1986). Factor analysis of data from Study 2 resulted in four dimensions for the SPCR: *task burden*, *role inadequacy*, *dominion* and *exclusion*. The scales of the SPCR are linked to the theoretical framework through the character of the four aspects of the caregiving role, as described in Tables 3.1 and 3.3.

SPCR Reliability

Pre-testing with 50 staff for Study 3 produced Cronbach's alpha coefficients of 0.88 (total stress), 0.72 (role stress) and 0.88 (burden). Reported Cronbach's alpha's for Study 3 were 0.71 for the *dominion* subscale, 0.70 for the *exclusion* subscale, 0.84 for the *task burden* subscale and 0.82 for the *role inadequacy* subscale (Maas et al., 2000). The Korean Study yielded Cronbach's alphas of 0.64 for the *dominion* subscale, 0.70 for the *exclusion* subscale, 0.84 for the *task burden* subscale and 0.82 for the *role inadequacy* subscale (Butcher et al., 2001). This current study yielded Cronbach's alphas of 0.69 for the *dominion* subscale, 0.79 for the *exclusion* subscale, 0.87 for the *task burden* subscale and 0.80 for the *role inadequacy* subscale.

SPCR Validity

Construct validity for the SPCR, as for the Caregiver Stress Inventory (CSI) which follows, were supported by analysing the correlations between the stress subscales of the two instruments using staff data from Study 3. The correlations for all subscales were statistically significant, ranging from 0.33 to 0.50, except correlations between *resident safety* in the CSI and *dominion* and *exclusion* in the SPCR. SPCR subscales of *dominion* and *exclusion* had low correlations with the *resident safety* subscale in the CSI ($r = 0.12$ and 0.17 respectively).

Caregiver Stress Inventory (CSI)

The 43-item CSI developed by Maas and Buckwalter (1990), measures the extent of stress experienced by staff caregivers associated with residents with dementia. Staff caregiver stress is described as the response by staff to incidents that occur in the daily care of residents with dementia (see Appendix B5). Each item is self rated by staff on a 7-point Likert scale (1 = not stressful, 7 = extremely stressful). The instrument required about 15 to 20 minutes to complete. The instrument was developed using a ‘critical incidents technique’, asking 50 residential care staff to describe a highly stressful event involving a resident with dementia during the previous week. Factor analysis using data from Study 3 identified four dimensions of stress related to care of the person with dementia: resident aggression, inappropriate behaviour, resident safety and the availability of resources for staff to assist in resident care. The scales of the CSI are linked to the theoretical framework through the character of the four aspects of the caregiving role, as described in Table 3.1 and 3.3.

CSI Reliability

For the CSI pre-intervention data collections for Study 2, internal consistency (Cronbach’s alpha) ranged from 0.90 to 0.95. The ranges of internal consistency coefficients for the subscales were: verbal/physical = 0.92; emotional/mental = 0.94 to 0.97; and knowledge/resources = 0.87 to 0.92. Cronbach’s alphas of each subscale reported for Study 3 were 0.91 for the *catastrophic behaviour* subscale, 0.83 for the *resident safety* subscale, 0.82 for the *resource deficiency* subscale and 0.99 for the total scale (Maas et al., 2000). The Cronbach’s alphas for Study 4 with Korean staff members were 0.87 for the *catastrophic behaviour* subscale, 0.91 for the

inappropriate behaviour subscale, 0.86 for the *resident safety* subscale, 0.85 for the *resource deficiency* subscale and 0.95 for the total scale (Butcher et al., 2001). The Cronbach's alphas for this current study were 0.94 for the *catastrophic behaviour* subscale, 0.94 for the *inappropriate behaviour* subscale, 0.87 for the *resident safety* subscale, 0.87 for the *resource deficiency* subscale and 0.97 for the total scale.

CSI Validity

Content validity of the CSI has been supported by the critical incident approach used to develop the items of the instrument (Maas et al., 2000). The CSI's construct validity was assessed by correlating the subscale and total scores with the subscale scores of the Maslach Burnout Inventory (MBI) (Maslach & Jackson, 1981). The MBI is a standardised, self-report questionnaire that measures the frequency and intensity of perceived burnout of individuals in helping professions. The MBI consists of three generalised scales: *emotional exhaustion*, *depersonalisation* and *personal accomplishment*. Hypothesised correlations of the subscales with other measures of theoretically derived variables have supported the validity of the MBI, and test-retest reliability estimates ranged from 0.53 to 0.82 for all six subscales (Maslach & Jackson, 1981). As hypothesised, correlations between the extent of stress measured by the CSI and the *emotional exhaustion* and *depersonalisation* dimensions of the MBI were moderate and positive, whereas the extent of stress and the *personal accomplishment* dimension of the MBI were moderately and negatively correlated in Study 1 (Maas & Buckwalter, 1990).

Attitudes Towards Families Checklist (AFC)

The AFC is a 16-item self-report instrument developed by Maas and Buckwalter (1990) to measure staff attitudes towards families of residents with dementia, including family visitation, family requests regarding care of their relative, and family participation in the care of their relative. Staff rate the items on a 7-point Likert-type scale (1= strongly agree: 7 = strongly disagree). A high score shows that staff have a positive attitude toward regular visitation from family members, family requests concerning care of the resident with dementia, and the family caregiving role for the relatives. The instrument consists of three subscales: *calming* (reflecting whether family caregivers are seen as having a calming or a disruptive effect on residents); *partner*; (reflecting whether family caregivers are seen as equal partners in care or

not; and *relevant* (reflecting whether family caregivers are seen as relevant to residents and staff). Thus the AFC assesses whether staff believe that family caregivers are disruptive, whether they are irrelevant to care and whether they should be partners in care (see Appendix B4).

AFC Reliability

Following pre-testing with 50 nursing home staff from Study 3, the AFC produced an internal consistency reliability coefficient (Cronbach's alpha) of 0.91 (Maas et al., 2000). Test-retest reliability with 15 staff at a 3-week interval was $r = 0.84$. Cronbach's alphas for the subscales from Study 3 were 0.64 for the *calming* subscale, 0.58 for the *partner* subscale, 0.55 for the *relevant* subscale and 0.74 for the total scale (Maas et al., 2000). The Cronbach's alpha for Study 4 were 0.56 for the *calming* subscale, 0.63 for the *partner* subscale, 0.55 for the *relevant* subscale and 0.70 for the total subscale (Butcher et al., 2001). The Cronbach's alpha for this current study were 0.68 for the *calming* subscale, 0.65 for the *partner* subscale, 0.53 for the *relevant* subscale and 0.70 for the total subscale.

AFC Validity

In alignment with the FPCR and SPCR, content validity for the AFC was assessed by a panel of gerontology nurses and social workers that reviewed and revised the instruments. Item selection was based on the limited literature published on family and staff members in SCUs and derived from the theoretical framework. A review of the literature at the time the AFC was developed revealed instruments that only measured staff caregiver perceptions for general RCFs, not for SCUs specifically. Thus no criterion measures were detected for further validation of these tools.

For staff caregivers, as for family caregivers, the scales are organised into four clusters corresponding to the four significant aspects of the caregiving role, described in Table 3.1. The character of each caregiving aspect differs for staff and families, reflecting the difference in the character of the caregiving roles and their relationships with the background theoretical framework (Maas et al., 2004).

Table 3.5 on the following page presents a summary of reliability measurements for each of the four staff instruments as they were modified.

Table 3-5: Summary of Staff Instrument Modification

Staff Instrument	Instrument Subscale	Pre-test* Internal Consistency Reliability 2000 (N=20)	Study 3* Internal Consistency Reliability 2001 (N=20)	Study 4* Internal Consistency Reliability 2001 (N=843)
KDT				
<u>Version 1 (20 items)</u>	Total	.80		
<u>Version 2 (33 items)</u>	Total		.54	.82
Staff Instrument	Instrument Subscale	Pre-test* Internal Consistency Reliability 2000 (N=60)	Study 3 Test-Retest Reliability 3 weeks 2000 (N=15)	Study 4* Internal Consistency Reliability 2001 (N=112)
AFC				
<u>Version 1</u>	Disquieting Partner – Relevant	$r = .91$ (3 subscales)	Test – Retest** $r = .84$ ($p < .001$)	
<u>Version 2</u>	Calming Partner Relevant	.64 .58 .61		.56 .63 .55
Staff Instrument	Instrument Subscale	Study 3 Internal Consistency Reliability Post Int 2000 (N=60)	Study 3 Internal Consistency Reliability Pre Int 2000 (N=60)	Study 4 Internal Consistency Reliability 2001 (N=112)
CSI				
<u>Version 1</u>	Verbal/physical behaviour Emotional/social behaviour Knowledge/ability/resources	.87 .91 .90	.94 - .94 .95 - .98 .92 - .96	
<u>Version 2</u>	Catastrophic behaviour Inappropriate behaviour Resident safety Resource deficiency	.91 .94 .83 .82		.87 .91 .86 .85
Staff Instrument	Instrument Subscale	Study 3* Internal Consistency Reliability 2000 (N=50)	Test-Retest Reliability (N=15) 3 weeks 2000 (N=15)	Study 4* Internal Consistency Reliability 2001 (N=112)
SPCR				
<u>Version 1</u>	Role stress Burden Total stress	.72 .88 .88	Test – Retest* $r = .89$ ($p < .001$)	
<u>Version 2</u>	Task burden Role inadequacy Dominion Exclusion	.84 .82 .71 .70		.61 .70 .70 .64

* Cronbach's Alpha

** Pearson's Correlation

Comparison of Reliability Measures – Australia and US

The following table presents a comparison between the current study and Version 2 of the Maas et al. study of internal consistency reliabilities for the KDT, and each outcome cluster measure for each instrument. Most of the Cronbach's Alpha coefficients identified in this study are similar to the Maas et al. internal consistency reliabilities. Notable differences in measures were in the outcome clusters of *physical care*, *management effectiveness* and *irrelevance*. It is assumed that the lower internal consistency measures for this study are because of the smaller sample sizes.

Table 3-6: Comparison of Reliability Measures: Australia and US

Aspect of Caregiving Role – Families	Family Outcome Cluster Measures	Cronbach's Alpha	
		Aust	NA
Knowledge of dementia	Knowledge	0.67	0.82
Relationship to care recipient	Emotional reactions to care recipient		
	<i>Loss</i>	0.76	0.73
	<i>Captivity</i>	0.78	0.81
	<i>Guilt</i>	0.75	0.70
Relationship to other caregivers	Perceived relationship with staff		
	<i>Conflict</i>	0.81	0.84
	<i>Consideration</i>	0.64	0.85
Adequacy of role performance	Perceptions of care		
	<i>Physical care</i>	0.53	0.97
	<i>Activities</i>	0.84	0.87
Impact of organisational performance	Perceptions of management effectiveness		
	<i>Management Effectiveness</i>	0.61	0.88

Aspect of Caregiving Role - Staff	Staff Outcome Cluster Measures	Cronbach's Alpha	
		Aust	NA
Knowledge of dementia	Knowledge	0.70	0.82
Relationship to care recipient	Emotional reactions to care recipient		
	<i>Inappropriate behaviour</i>	0.94	0.94
	<i>Aggression</i>	0.94	0.91
Relationship to other caregivers	Perceived relationship with family		
	<i>Dominion</i>	0.69	0.71
	<i>Exclusion</i>	0.79	0.70
	<i>Disruption</i>	0.68	0.64
	<i>Partnership</i>	0.65	0.58
	<i>Irrelevance</i>	0.53	0.61
Adequacy of role performance	Perceptions of caregiving		
	<i>Role inadequacy</i>	0.80	0.82
	<i>Task burden</i>	0.87	0.84
	<i>Resident harm</i>	0.87	0.83
Impact of organisational performance	Perceived organisational support		
	<i>Resources</i>	0.87	0.82

Pilot Field-Testing of Instruments

Because of the rigour associated with pilot testing and instrument development in the Maas et al. research and the minor modifications required to the questionnaires, pilot field testing of the instruments in this study was minimal. Two family caregivers and two staff caregivers who did not participate in the study were approached prior to the baseline data collection and agreed to complete the surveys. The testing was primarily undertaken to ascertain the length of time required to complete each questionnaire and to check the minor modifications to language use in the instruments. The participants reported that there were no difficulties associated with completing the questionnaires.

The following section presents an overview of the quantitative pre- and post-intervention data collection.

Quantitative Pre and Post-Intervention Data Collection

Quantitative data were collected during the first month pre-intervention (Time 1) and at one month (Time 2), five months (Time 3), and nine months (Time 4) post-intervention. Figure 3.3 below summarises the quantitative data collection method for family and staff.

Figure 3-3: Quantitative Data Collection Method

Families	PRE-TEST		POST-TEST		
	Month 1		Month 2	Month 5	Month 9
Intervention Site	T 1	X	T 2	T 3	T 4
Control Site	T 1	-----	T 2	T 3	T 4

X = Implementation of FIC 'Placebo' Intervention with family caregiver

T = Data collection at each time period

Staff	PRE-TEST		POST-TEST		
	Month 1		Month 2	Month 5	Month 9
Intervention Site	T1	X₁ ⇔ X₂	T 2	T 3	T 4
Control Site	T 1	-----	T 2	T 3	T 4

X₁ = Implementation of FIC Intervention with family caregiver

X₂ = Begin implementation of FIC partnership with family caregivers

T = Data collection at each time period

The following section presents a description of the qualitative data collection procedures.

Qualitative Family Caregiver Interviews

Interviews with family caregivers were conducted at baseline, prior to the intervention and in the final month following completion of the 9 month study period. The intent of the interviews was to ascertain family caregivers' responses about institutionalisation of their relative with dementia, changes in their caregiver roles and responsibilities following placement, their perceptions of stress and satisfaction associated with relocation of their relative to residential care, and evaluation of care and relationships with staff and other family caregivers.

Interview Guide for Qualitative Data at Baseline

A semi-structured interview guide was used which posed questions focussing on four main areas of family caregiving both prior to and after their relative with dementia was admitted to residential care. The four main content areas were: 1) care provided for the relative with dementia prior to placement in the facility; 2) the process and feelings associated with placing their relative with dementia in the facility; 3) perceptions of care relationships with the resident and staff; and 4) evaluation of care in the facility. Family caregivers were encouraged to talk freely about their perceptions and experiences. Interviews lasted from one to one and a half hours. The interview guide is presented in Appendix C1.

Interview Guide for Qualitative Data Post-Intervention

A semi-structured interview guide was also used following completion of the intervention to explore family caregivers' perceptions of the success of the four aspects of the intervention: 1) the education manual; 2) the partnership agreement (intervention site only); 3) the benefits of ongoing contact with a staff member; and 4) the future of a partnership model of care. Examples of questions asked during the post-intervention interview were: 'Do you feel that you are more involved in the care of your relative now than you were at the beginning of the study?' and 'Have there been any benefits for you as a family caregiver from the involvement with a staff member?' The full interview guide is presented in Appendix C2.

The qualitative findings from the baseline interviews are presented in Chapter Four. The post-intervention findings are presented in Chapter Six. The following section presents a discussion of research rigour and ethical considerations associated with the study.

Research Rigour

In order to achieve and maintain quantitative data integrity the interpretive processes were decided upon with the study supervisors before the data analysis. Regular meetings were then held with the supervisors so that appropriate expertise and guidance was provided during data collection and analysis. The rigour of the quantitative inquiry was enhanced by building on an empirically validated intervention based on a clear theoretical model (Polit & Beck, 2008).

During the qualitative data analysis regular discussion with supervisors, as experts in their field, allowed for thorough examination of emerging themes and categories in the data. The importance in qualitative inquiry of ‘trustworthiness’ of the data was addressed by thoroughly considering the research design, data collection, interpretation and communication (Mays & Pope, 1995; Polit & Beck, 2008).

Ethical Considerations

Ethical clearance for the study was obtained from the Griffith University Human Research Ethics Committee and accepted and supported by the executive management and site management at the RCFs. Family caregivers who gave permission were contacted by telephone or during family information sessions and invited to participate in the study. Staff members were approached individually, either face to face, by telephone or at staff meetings. Willing participants were given an information sheet and a consent form confirming they understood the terms of the study before they agreed to participate. The information sheet provided an overall description of the study, and was formalised through the presence of the combined logos of the service provider as well as the university through which the Researcher conducted the study (see Appendices H1 and H2).

It was made clear to the participants that they were free to withdraw from the study at any time. Participant anonymity was achieved through the use of coding and

pseudonyms. All data were de-identified at the time of data entry, with a coded spreadsheet kept separate from the data. All direct quotations from interviews were checked to ensure that neither the family caregiver nor their relative with dementia could be identified. Once the interviews were transcribed, all audio taped interviews were erased.

Adherence to privacy principles was achieved by ensuring that staff gave information to families only after they indicated that a formal approach by the Researcher was made. Similarly, privacy principles were upheld with staff and families by ensuring that management only provided them with information about the study after formal discussion with the Researcher. In terms of confidentiality there was a risk that, because of the stigma associated with dementia, some families may not have accepted their relative's formal diagnosis during initial discussion about participating in the study. This potential problem was addressed by ensuring that the diagnosis was clearly stated in the resident's care plan and confirmed by facility nursing management prior to approaching family caregivers.

Prior to the study it was agreed with management and indicated within the consent forms that if poor care practices were observed or indicated by staff or relatives that these would be reported to management. There was also a commitment from the organisation that if the intervention proved to be successful the participants at the control site would receive its successful elements by incorporating them into care practice. Finally, as a result of her commitment to this study, Professor Meridean Maas agreed to provide additional documentation and analysis not available in the published papers.

The statistical procedures used in this study are presented in the next section.

Data Analysis

Statistical Procedures

This mixed method, sequential two-phase design study aimed to replicate the theoretical framework and model of care developed in the Maas et al. research and implement the intervention in two Australian RCFs. The statistical procedures used, therefore, aimed not only to analyse the outcome effects of the FIC intervention in this

study but also to compare them with the Maas et al. study. The specific aims of the quantitative phase of this study were to:

1. Identify between-group (control and FIC intervention group) differences prior to the intervention. Frequencies, means and standard deviations were calculated as appropriate on the demographic variables. Chi-squared analysis was used to detect site demographic differences for family and staff caregivers;
2. Identify between-group (control and FIC intervention group) differences post-intervention at three weeks, three months and nine month time intervals; and
3. Describe within-subject site changes, post-intervention at each time interval.

Quantitative data were entered and analysed using the personal computer software SPSS 14 (2005). The reliability (internal consistency) of each outcome cluster was assessed using Cronbach's alpha for reliability and are presented in Table 3.6.

Group Comparison Statistics

A univariate (ANOVA) approach to repeated measures was used to analyse the outcome effects of the intervention on family and staff caregivers. Independent t-tests were conducted to identify any significant (between subject) differences between the control and the intervention sites, both pre and post-intervention. Analysis of covariance (ANCOVA) further supported and identified any significant baseline differences between the control site and the intervention site. Paired sample t-tests (within subject repeated measures) were used to identify significant differences between the baseline measures and the three follow-up data collections post-intervention. A *p*-value of 0.05 was used to determine statistical significance and two-tailed tests were used for all statistical tests. The results of the statistical tests are reported in the pre and post quantitative findings Chapters Five and Six.

Descriptive Statistics

Descriptive statistics were used to explore and describe the characteristics of the samples and to compare the demographic characteristics of the family and staff caregiver groups (Polit & Beck, 2006, 2008). Chi-squared tests were used to make inferences about the characteristics of the samples and to identify any significant differences. Descriptive statistics were also used to present site comparisons of mean scores and to compare with the Maas et al. study results to identify any cross cultural differences in family stress and satisfaction scores.

Intention to Treat Analysis

Intention to treat analysis was used to prevent bias caused by loss of participants and therefore missing data at either of the four observation periods in the study (Altman et al., 2001). This method, which addressed the problem of missing data by using the last observation carried forward, addressed the obstacles associated with collecting longitudinal data over a nine month time period, either from participant attrition due to resident death or staff turnover, or inability to complete the observations at one of the interim data collection periods.

The following section discusses the limitations identified in this study.

Study Limitations

This is the first study in Australia to evaluate the effectiveness of the FIC intervention in residential dementia care. Evidence suggests that empirical studies examining the efficacy of interventions in the clinical environment require optimum evaluation conditions to control for potential bias and confounding factors (Gordis, 2004). One major limitation in this study were the logistics and resource constraints associated with truly randomising the sample at each site. This limitation was overcome by randomly assigning one site as the control and the other as the intervention.

The next major limitation was the restricted size of the family and staff caregiver populations at each site from which the study sample could be drawn. The preliminary estimate for this study of a sample size of 60 family caregivers and 60 staff caregivers across the two sites was calculated to ensure a medium effect size and an alpha level of 0.05. The sample size calculation provided a realistic basis for

successful recruitment of the required number of family and staff caregivers at each site (Altman et al., 2001). The calculation was also supported by the successes of the Maas et al. study, with statistically significant positive findings for three out of the four family caregiver outcomes and one of the four staff caregiver outcomes. However, these limitations have increased the difficulties in determining whether the impacts of conditions at each site may have been sufficient to bias the outcomes effects of the intervention. It was determined, therefore, that in the absence of the presence of statistically significant findings, descriptive comparison of these study outcomes with those of the Maas et al. study would provide additional evidence of intervention effects.

Summary

In summary, the qualitative and quantitative phases of this mixed method, sequential two-phase design study aimed to further empirical knowledge and understanding of family caregiver roles and partnerships in residential dementia care. The aim of the quantitative phase of the study was to build on our understanding of the FIC intervention by testing it in an Australian context in a controlled clinical trial. The purpose of the pre-intervention qualitative phase was to explore the person-environment fit and role theory frameworks that underlie and guide the FIC intervention, therefore enhancing the quantitative data assumptions of internal validity and causality (Brink & Wood, 1998; Ezzy, 2002). Accordingly, the sequential design not only serves the purpose of establishing the factors identified in the quantitative analysis, but also identifies potential threats to internal validity when using the same set of predictor variables as in the Maas et al. study (Buckwalter, Maas, & Wakefield, 1998).

The family and staff instruments used are replicated from the Maas et al. study, as are the knowledge, stress and satisfaction outcome measures. The instruments were assembled into four clusters corresponding to the four aspects of the caregiving role as described in the theoretical framework.

University ethical approval was given to conduct the study. Participant confidentiality was maintained to protect the rights of participants. The qualitative and quantitative findings are presented in the following chapters.

CHAPTER 4

FAMILY CAREGIVER PRE-INTERVENTION QUALITATIVE FINDINGS

Introduction

This chapter explores the experiences of a sample of ten family participants, drawn from the larger study group prior to the FIC education intervention. Analysis of this data formed an integral component of the mixed method sequential two-phase design study, and aimed to complement the quantitative analysis by obtaining and analysing “contextualized information” about family member perceptions of their caregiving role following placement of their relative in residential care (Creswell et al., 2003; Tashakkori & Teddlie, 1998). The major areas associated with residential care placement have been identified in the Maas et al. study and linked to the theories of person-environment fit and interaction and role theory. The conceptual basis of the qualitative research framework - the semi-structured interview guide - supported the person-environment fit and role theory frameworks.

Participant Sample

The purposive sample of ten interviewees was representative of the larger sample of 57 family members (presented in Table 4.1) enrolled for the study at both sites. The profile of relationships to the resident with dementia was; daughters (5), sons (2), female spouse (2) and male spouse (1), ranging in age from 46 to 88 years. All family members were relatives of residents with dementia in residential care, living either in the hostel (low care), nursing home (high care) or the Special Care Unit (SCU) section of the two facilities, with five family members drawn from each site. Education levels were generally high, ranging from diploma to postgraduate degree, with the exception of one spouse whose education ceased at primary level. Table 4.1 summarises the characteristics of the qualitative participant sample.

Table 4-1: Summary of Qualitative Participant Sample Characteristics

Participant (pseudonyms)	Gender	Age	Relationship to person with dementia	Education Level	Occupation
1. Janice	female	58	daughter	diploma	Self Employed
2. Natalie	female	51	daughter	diploma	Manager
3. Clint	male	53	son	diploma	Manager
4. David	male	88	husband	primary school	Retired (tradesperson)
5. Sally	female	78	wife	certificate	Nurse
6. Jenny	female	75	wife	postgrad	Professional
7. Cathy	female	49	daughter	diploma	Retired
8. Ronald	male	56	son	postgrad	Professional
9. Jane	female	45	daughter	certificate	Clerical
10. Madeline	female	49	daughter	diploma	Massage therapist

In-depth, semi-structured interviews were conducted prior to collection of the baseline data and commencement of the intervention. Participant anonymity was achieved through the use of coding and pseudonyms. The semi-structured interviews occurred in a private location at the aged care facilities, or at the home of the participant if requested. The semi-structured interview guide replicated the content areas covered in the Maas et al. study interview schedule, and explored:

1. Caregiving prior to placement (including diagnosis of dementia);
2. The process and feelings associated with placement;
3. Perceptions of the care relationships between family and staff;
4. Evaluation of care in the facility (Kelley & Maas, 1999).

These areas were explored through the use of probing questions, giving participants the opportunity to “tell their story” and voice their views. The questions were worded to elicit knowledge based on experience and feelings (Holloway & Wheeler, 1996). For example: “What were your feelings when you were making the decision for aged care facility placement and then during the actual relocation of your relative?” “How have you been involved with the care for your relative since he/she has come to the facility? Tell me about it.” Findings were identified using a form of content analysis, known as thematic analysis, mindful that in the context of aging research and the

trajectory of the dementing process, “themes are markers of process, not fixed structures” (Grbich, 2007; Luborsky, 1994). Mindful too, that as the course of the disease progresses, its impact on the nature and meaning of the individual caregiver experience finds its own unique discourse (Butcher et al., 2001; Luborsky, 1994). As with the Maas et al. study, Luborsky’s recommendations for systematic analysis were achieved using the following procedure:

1. A simple reading of the transcripts was performed to get acquainted with them. Notes were not taken at this time.
2. A second reading was conducted to identify topics. These major topics were summarised in a phrase or code word and written on the transcript, as well as on a master sheet for comparison within and across transcripts.
3. These phrases and topics were listed as candidate themes.
4. The candidate themes were narrowed down and summarised, using frequency of recurrent topics and grouping together of compatible or common themes (Kelley & Maas, 1999; Park, 2001).

During the qualitative data analysis these candidate themes were used for discussion with the supervisors who, as experts in qualitative research, confirmed the four main themes that emerged from the four content areas described above. These main themes were: (1) increasing burden and isolation; (2) relentless grief; (3) seeking connection and meaning with staff; and (4) looking after the person. The purpose of this approach was to ensure that these procedures were adequate and ensure no new themes emerged (Kelley & Maas, 1999).

The family interview guide is presented in Appendix C1. A summary of themes, topics and number of topics in the four content areas is presented in Table 4.2. A descriptive analysis of the four themes follows, supported by verbatim statements from interviewees about their views and experiences.

Table 4-2: Summary of Patterns, Topics and Themes (N=10)

Family Caregiver Content Area*	Themes	Topics (candidate themes)	Number of Topics	Number (%) of Interviews	
Caregiving prior to admission	Diagnosis of dementia	Denial/lack of acceptance	25	10	
		Declining abilities and social skills	22	9	
		Memory loss	21	8	
		Symptoms more evident after trauma	16	5	
		Depression	9	3	
	Increasing burden (captivity)	Too difficult to handle	30	10	
		Filial/spousal role change	28	10	
		Respite not successful	20	10	
		Loss of social support	19	8	
		Adaptation to care giving role	18	8	
		Stoical independence	14	7	
	Feelings about placement	Relentless grief	Mixed feelings of relief/guilt	30	10
			Filial/spousal responsibility	27	8
			Need for counselling	18	6
Distress/trauma of placement			16	6	
Loss of control			15	5	
Conflict with resident			8	3	
Relationship with staff	Seeking connection and meaning	Seeking increasing understanding with staff	22	8	
		Desire to increase knowledge	18	7	
		Sense of isolation	17	6	
		Lack of communication	17	6	
		One contact point with staff	15	5	
		Conflicting goals/roles	9	5	
		Interaction with other family caregivers	8	5	
Evaluation of Care	Looking after the person	Social interaction	30	10	
		Physical care/nutrition	29	10	
		Maintaining personhood	28	9	
		Physical environment	28	8	

* From Maas et al. (2000) interview schedule

Caregiving Prior to Admission - Increasing Burden

The first question in the caregiver interview guide related to the care provided by families at home prior to admission. As each individual recalled the circumstances surrounding this time there was a recurrent pattern of increasing burden of care, at times associated with uncertainty about a formal diagnosis of dementia. A number of family members talked about the occurrence of a crisis or significant event which seemed to exacerbate the early signs of dementia, or at least highlight them more starkly. This scenario of slow unveiling, typical of the progress of dementia, is explained well by one daughter:

Yes, four years ago this May, now I suspect there was a bit of dementia in dad before that and mum was picking up the pieces of all that. When we lost mum I used to go across and spend nights with dad I started to see things and for a long time I didn't know if it's dad in his grief and distracted.

Interview #1, Janice

The sense of uncertainty, about the present and the future, was a common thread through the discussions, one of a number of contributing factors to the increasing burden of care. For some the physical isolation caused by geographical distance from services and family played a part in the delay of dementia diagnosis, and provision of suitable support. For those persons with dementia living with his/her partner the compensatory role played by the spouse also impacted on both the willingness to pursue and the ability to accept a formal diagnosis. Then, for some, the denial caused by lack of knowledge and fear of the disease itself prevented spouses from seeking help. One female spouse who had commenced attending Alzheimer's meetings expressed the sense of uncertainty as:

Yes they tell me at Alzheimer's [meetings] that the day they pronounce your relative has Alzheimer's, deep down is the day you start grieving.

Interview # 5, Sally

Concurrently, the increasing care burden resulted in deteriorating health for most spousal family caregivers and an inability to manage the relative with dementia at home. Statements from spouses like “*she was becoming too difficult to handle*”, “*needed constant supervision*” and “*awake all night*” clearly reflected the increasing

challenges of continuing care at home. For most filial respondents there was a sense that the increasing challenges associated with taking care of their parent at home were identified too late, either because of spousal compensation or because both the person with dementia and the spouse were in denial about the disease. Consequently the early signs of memory loss, depression, declining abilities and social skills were often missed by the younger members of the family, as described in the following passage:

... it was only say in between '95 and 2000 that things that were apparently an issue with dad really came to the surface, ... when his short term memory, he couldn't remember the names of people ... and that's when mum picked it up and he was still driving and boating and fishing and things like that. Dementia, Alzheimer's ... wasn't talked about in terms of well we're concerned about dad's short term memory loss ...they did not consider the consequences or make plans for the worst case scenario.

Interview #3, Clint

For the older generation it was evident that despite their declining independence they strived to uphold a level of stoicism and exhibited a general reluctance to call on their children, or health professionals, for help. This meant that for many offspring the emergent role changes, together with the obligation to support ailing parents brought its own gamut of caregiver burden in the form of guilt, frustration and anxiety about their parents' wellbeing. Their increasing sense of burden became more apparent as they described their attempts to juggle their own family and work commitments with the increasing needs of their parents. As related in the following passage, the guilt presented itself in a number of ways, from an expression of regret for not being able to provide ongoing care at home to calls for financial help to bridge the gaps in professional home care:

... there was a huge void, just poor families out there ... from that to being in care, there's this huge gap if families can't step in and do it ... dad probably could have gone home and been there another six months if we'd been able to fill that gap and I guess if you had buckets of money you could, we could have paid for nursing support but that's expensive beyond any of our means.

Interview # 1, Janice

Overlaying the increasing difficulties with providing care at home was the perceived gap in community care options available. Respite care proved unsuccessful for all participants, mainly due to the increased negative behaviours of the person with dementia, both in respite and when they returned home. It was clear that the respite

facility environment itself was often not suitable for the specialised needs of the person with dementia, as reflected in the words of one respondent:

...completely disorientated the poor man ... it was a very closed environment, a hallway, a room and that was it.

Interview #2, Natalie

This finding is supported in Neville and Byrne's review of respite research which provides evidence that, instead of short periods in respite mitigating behavioural problems, it may actually serve to exacerbate them (Neville & Byrne, 2006). The lack of suitable community care and respite options available also presented more problems for employed offspring who tended to make the decision earlier to place their parent in residential care. In two instances the increasing burden of care resulted in intergenerational conflict as all family members struggled with the changing needs of the person with dementia and their changing caregiver roles.

Alternatively, spouses tended to maintain their roles as caregivers for as long as possible, if only to extend their enduring association with their life long partners. The prevailing feeling was that they had adapted to the challenges of the caregiving role but it was most often the physical demands that forced them to seek care. This was captured in such statements as "*... incontinence set in, she'd be up at night for hours, wouldn't go to bed ...*". In the meantime there was a general feeling that their lives were eroded by a slow loss of independence and loss of social contact. These changes were described by such terms as "*I was very isolated, ... I cared for her in a world of our own really ... friends have dropped off*". Behavioural changes in the person with dementia could also cause additional stresses, described by one spouse as "*he was very paranoid and he was aggressive. Not physically aggressive, more mentally aggressive*". Nevertheless, it was more likely the offspring who initiated the process of seeking placement, as they witnessed the onerous nature of caregiving responsibilities and their detrimental impact on the "well" parent:

Mum became very withdrawn ... she had no life of her own. She lost her social graces, lost friends.

Interview #3, Clint

It was generally clear that because of the long-term trajectory of dementia (average time requiring care at home was four years) the role changes for family caregivers prior to admission were subtle, and at times insidious with varying degrees of detrimental physical and emotional impacts for all family members. The prevailing message surfacing from the interviews supports the view of Maas (1991) that dementia is “truly a family problem”, and as the interviews progressed it became clear that the problems for families did not cease at the residential facility door.

Feelings about Placement - Relentless grief

When respondents were asked how they felt when their relative was placed in residential care, the reply was overwhelmingly that of loss, sadness and guilt. Initially for offspring, and some spouses, there was a sense of relief, knowing their parent would be safe and looked after. *“We were concerned with her quality of life, her safety.”* However, more overwhelming than the relief were the ongoing feelings associated with loss, such as *“Initially it’s such a wrench and there’s guilt in having a parent in care,”* and the sadness, such as *“it’s affected all the children because they’re just so sad.”* This sense of relentless grief was described by one son as:

Mum talked about guilt ... she said it’s guilt, it’s grief, sadness, regret, all that and you don’t think this will happen.

Interview #3, Clint

There was a general sense from participants that they were forced to make a decision about residential placement because the situation had reached crisis point, reflected in such phrases as *“it happened very quickly”* and *‘it was all so new, the whole thing.’* None of the respondents felt they had been prepared for the transition to care, and the newness of the situation seemed to contribute to the rawness of their grief, and the associated stress and trauma of placement. Most participants talked about their responsibilities in the spousal or filial role, and how they might find a place within the facility.

All the female respondents talked about the need for counselling during this time, and at least half of those had initiated professional help privately. One daughter expressed her needs as follows:

... I actually had professional help outside ... over the other side is I just don't seem to be able to do enough. Can't come enough, can't say enough, can't give enough. And the most difficult thing to deal with is knowing the conversations that won't be had because the mind is going."

Interview#1, Janice

The emerging elements of relentless grief and isolation felt by families clearly illuminate the gaps in support from health professionals in the community for primary family caregivers. The impacts of the lack of support seem more profound for spouses who seem to have hardly begun to accept that their partner has dementia until the person with dementia is placed in residential care (Moyle et al., 2002). It is as if the state of denial acts as a protective shield, allowing caregivers to continue on at home and providing a sense of hope in the enduring family structure. When admittance to residential care does finally happen, it seems that family roles finally begin to break down, slowly eroding that sense of hope. One husband aptly expressed his feelings during this time as: *"It takes a bit of mental handling ... seemed to get worse when she was placed"*, and a wife described it as *"feeling the man is gone"*, accompanied by a loss of control and sense of meaninglessness. Another wife talked about the relentless, insidious nature of the disease process and the sense of hopelessness it brings as follows:

Because you realise that there's no cure, like sometimes if you're told you have cancer you know that there's a good chance that it can be cured..... we've got no future you know, our future's almost finished the way I look at it, we can't plan ...

Interview #5, Sally.

The feelings of grief seemed to be compounded when families were not sufficiently orientated to the residential facility resulting, for some, in feeling that the *"system takes over"*. Clearly there is a sense, particularly for spouses, that dealing with the processes of admission and its associated major upheavals to their lives is too onerous for them during this time. Consequently the financial and administrative aspects of care tend to become a shared filial responsibility, especially if, as one son stated, *"Mum can't get her head around the "Ageing in Place" concept"*. Indeed, after the person with dementia is in permanent residential care, some spouses find it not easier, but increasingly difficult to cope with the loss of, and separation from, their lifelong partner. Furthermore the behavioural changes associated with the person with

dementia's disorientation may add another layer of confusion and distress for family caregivers. These feelings were more often described by family members if the person with dementia was admitted to the hostel environment, where there was very little staff presence compared to the SCU. What then eventuates is another round of grief with, yet again, very little support from, or communication with, staff educated and trained in dementia care.

As discussed previously the deteriorating trajectory of the disease on the person with dementia, and the associated caregiver burden for families does not necessarily subside after admission to residential care (Kellet, 2000). In fact, for family caregivers who had experienced their relative with dementia move from one section of the residential facility to another, the grief associated with loss and deterioration often returned with each move. One daughter expressed her distress and sense of disconnection at the suddenness of the change when her mother was transferred from the hostel to the nursing home as *"I felt like she had passed away"*. The respondent's sense of isolation was compounded by a lack of orientation to the new environment, together with new and different staff, whom she hardly saw. The daughter's sense of disconnection became a major barrier to coming to terms both with her evolving grief and building relationships with staff.

Relationships with Staff - Seeking Connection and Meaning

To increase understanding of the relationship between staff and family caregivers respondents were asked questions related to information about the kind of care given and family involvement in the care.

Most respondents felt that they had not been encouraged to be involved in the care of their relative. These feelings were exacerbated by the sense of isolation and powerlessness in the initial days of placement, with very little sense of the facilities *"embracing families"* and a paucity of communication. There was a general feeling that not enough information was provided initially and there was very little contact with staff. It is clear that whilst families had reached a level of acceptance about their inability to continue to provide care at home, the obligation to remain involved continued. When prompted, respondents spoke in detail about how they believed they

could play a part in the care of the person with dementia, and wished for a more communicative relationship with staff based on common understanding. From a family caregiving perspective they felt that they still had an ongoing role and responsibility to play in communicating their relative's disabilities (for example, hearing and sight loss) and needs (for example, food dislikes and likes) to staff. This sense of ongoing commitment is captured in the words of one son:

We are the ones who know dad, and know he is trying to communicate – we have learnt to read between the lines.

Interview #8, Ronald

Family members generally expressed a desire to build understanding rather than clash with staff when establishing their roles within the facility. When family members did describe their interactions with staff there was a positive emphasis on their '*abiding sense of care and commitment*' to the residents. Family members also accepted that, particularly in relation to physical care, staff were responsible for the person with dementia and had confidence in their skills in dementia care. In order to improve their sense of isolation they expressed a desire to build relationships with staff so that they could be guided by them in dementia care. All participants stated that they would like to improve their own knowledge and understanding about dementia, and to be more involved in their relative's care. They believed that building relationships with staff through regular communication would create the sense of meaning and connection they sought. A greater proportion of the participants expressed their preference for contact with one staff member and for more continuity of staff in the different sections of the facility, as described in the following statement.

I would have liked to have more feedback from staff... haven't been told about change of staff and I find that very confronting because you rely on people you know and have talked to before.

Interview #2, Natalie

Moreover, when asked about the function of the different areas within the residential facilities, most respondents still felt at a loss to explain the differences. They did not understand the rationale behind such areas as the SCU and its role as a dementia specific area of the facility. They also expressed an interest in learning how better to communicate with the person with dementia through such avenues as reminiscing. However, because of the general lack of communication with staff, families did not

feel confident making an approach about dementia and could not comment about staff's level of knowledge of such areas. Indeed, families generally found relatives of other residents with dementia more supportive in understanding their situation from the perspective of 'the person' and how they may better care for their relative with dementia.

Evaluation of Care - Looking After the Person

The final content area, evaluation of care, explored the best thing participants had found the residential facility provided for their family member. Further questioning in the specific areas of physical care, the environment, social/recreational activities and specialist dementia care provided a more in-depth understanding of family perceptions of residential care. Overall, respondents expressed a general satisfaction with the environment, the level of physical care, and the *"attitude of staff, their friendliness and obvious sense of care for the patients who are there"*. However, at the intervention site there were a number of concerns about the suitability of the hostel staffing ratios and the suitability of the environment for their relative, particularly if they were left alone for long periods of time. For similar reasons, environmental concerns were expressed about the physical layout of the nursing home at the control site, which was a large area characterised by long corridors and limited opportunities to see other people or staff. The emerging concerns emphasised the importance of the interplay between physical design, the environment, and the level of care in providing for the needs of the person with dementia.

The other consistent family concern related to *"gaps in care,"* especially at weekends. These gaps in care particularly related to lack of social interaction and companionship, described as *"consistency of presence of people around"* and physical activities, such as walks. Some respondents felt that more informed support and more staff were needed to reduce this isolation. There was a general feeling that the SCU environment more adequately catered for resident's social and physical needs, whether they were more or less active. As reflected in one respondent's comment whose relative was transferred to the SCU, *"as far as the social focus and stimulation side, that's certainly an improvement"*. All family caregivers agreed that the SCU environment provided a calming atmosphere for the person with dementia and

provided more interaction in terms of consistent staff presence and that of other residents.

When family participants were asked about physical care and nutrition, whilst overall comments were positive, other concerns came to light. There were the difficulties, particularly for spouses, with confronting the ongoing feelings of losing control of 'the person' related primarily to the loss of physical intimacy as they slipped further away from them. When asked about satisfaction with physical care, the majority of responses were positive, particularly in relation to grooming, cleanliness and general appearance. However, as expressed in the following quote, a number of families found it difficult to accept seeing their family member in other people's clothes:

... obvious that she is bathing and wearing clean clothes, her hair and grooming are being attended to, she is eating much better, so certainly that's a positive ... she is wearing other people's clothing, I guess that's a very difficult thing to control, in a facility like that.

Interview #8, Ronald

These comments once again illuminate family members' sense of loss of 'the person', and the underlying notion that staff may not be connecting with their relative in a meaningful way. Family members wanted to recall the person with dementia's familiar persona and image, outwardly represented by their clothing. The loss of that familiar image is yet again the loss of something over which they still had control at home, but did no longer, due to constant changes within the context of the disease process and institutional care (Moyle et al., 2002). On a more fundamental level the following statement by a spouse captures, despite the changes, the essence of their ongoing role: *"it's my obligation to take care of him and that's what I have to do"*. This sense of maintaining involvement, no matter how potentially stressful, is supported by other studies (Bauer, 2006; Dellasega & Nolan, 1997; Kellett, 2000).

As the dementia progresses there is a tendency for family caregivers to seek out further information from staff about relatives' care. Respondents talked about their preference for one contact point with staff but were very conscious about staffing levels and low staffing ratios. Nevertheless, it was clear that as the person with dementia becomes less able to express his needs, this is the time when the family's

need for communication increases. Their overriding concern is for the wellbeing of ‘the person’ and to know that when they are not there someone may be explaining to their relative what is happening. The following passage reflects the level of disheartenment felt by family members, as they see their loved one deteriorate:

It’s tragic to think what’s going on inside ...it’s awful when you know someone’s trying to tell you something and you’ve no idea what they’re saying.

Interview #2, Natalie

However, with too few staff to provide family members with reassurance, the resulting disheartenment and associated stress inevitably presents as dissatisfaction with care.

Conclusion

Family caregivers are already feeling the burden of care when their relative is admitted to the aged care facility. This burden is compounded by a sense of isolation due to facility design, lack of understanding of the disease and the grief process. The transition to the new environment is made more difficult if the sense of isolation is perpetuated. Families desire more involvement in care through a sense of connection and meaning with staff. They do not relinquish responsibility for their caregiving role.

There is an expressed desire from family caregivers to increase their understanding and knowledge of dementia and dementia care by establishing an ongoing relationship with a staff member. However, their experiences of lack of involvement with staff and insufficient orientation to the facility during admission have, for some, led to dissatisfaction with care. Family caregivers acknowledge that a sense of involvement and connection with staff can provide a sense of meaning in an otherwise new and confusing environment, and that the maintenance of family involvement in the care of their relative opens the way for increased focus on “the person” with individual needs.

The next chapter presents the quantitative family caregiver findings, both pre- and post-intervention.

CHAPTER 5

FAMILY CAREGIVER PRE AND POST-INTERVENTION QUANTITATIVE FINDINGS

Introduction

This chapter presents the quantitative findings from the analysis of the family caregiver outcomes, as measured by the FIC instruments described in detail in Chapter Three. The chapter firstly aims to describe the demographic, family caregiver and resident characteristics of the study sample and to compare the control site and intervention site at baseline (Time 1). Secondly, the extent of family caregiver involvement resulting from the minimum dose of the intervention is reported. Thirdly, the pre-intervention and post-intervention within subject and between group ANOVAs are presented as guided by the hypotheses identified in Chapter Two for Time 1, Time 2, Time 3 and Time 4. Finally, a descriptive analysis of mean score comparisons across the study sites and with the Maas et al. study results at Time 1 and Time 2 is presented to ascertain and illuminate any cross cultural differences in the findings.

Site Comparison of Family Caregiver Demographics

There were 27 family caregiver participants at the control site and 30 at the intervention site. The average age of participants at the control site was 58 years, compared to 60 years at the intervention site. The majority of participants were Australian born, representing (n = 24) 88.9% at the control site and (n = 26) 86.7% at the intervention site. At both the control and the intervention sites the majority of participants were female (n = 15, 55.6% and n= 24, 80.0% respectively). The number of married participants was similar at each site, with (n = 20) 74.1% married at the control site and (n = 22) 73.3% married at the intervention site. Employment status differed at each site, with (n = 11) 40.7% retired at the control site and (n = 18) 60.0% retired at the intervention site. Education levels were high at the intervention site with (n = 21) 70.0% achieving tertiary level compared to (n = 16) 59.3% of respondents at

the control site. Occupational status also indicated a high level of professionals and managers at the intervention site (n = 15), 50% compared to (n = 9) 33.3% at the control site. Chi squared tests detected no significant differences in demographic characteristics for the two sites. Demographic characteristics are summarized in Table 5.1.

The highest proportion of caregiver participants at each site were daughters, representing (n = 12) 44.4% at the control site and (n = 16) 53.3% at the intervention site. The proportion of spouses differed at each site, with (n = 4) 14.8% at the control site compared to (n = 8) 26.6% at the intervention site. Accordingly, the reduced proportion of spouses represented a greater percentage of sons (n = 10, 37.0%) at the control site than spouses (n = 4, 14.8%), compared to the intervention site (n = 4, 13.3% sons and n = 8, 26.6% spouses respectively). There were also more males at the control site (n = 10, 37.0%) than at the intervention site (n= 4, 13.3%). Chi squared tests detected no significant differences in caregiver characteristics for the two sites (see Table 5.1).

In summary, the family caregiver demographics for each site in this study were not significantly different. A summary of demographic characteristics is shown in the table on the following page. Included in the summary are the family caregiver characteristics of the Maas et al. study sample. The sample comparisons will be examined further in Chapter Eight.

Table 5-1: Summary of Family Caregiver Demographics

Demographic Characteristic	Control Group n (%)	Intervention Group n (%)	NA* N = 174 n (%)
Age			
Mean	57.8 (12.2)	59.4 (13.5)	61 (12.7)
Median (Range)	(45-86)	(45-88)	
Nationality			
Born in same country	24 (88.9)	26 (86.7)	164 (94.3)
Born in another country	3 (11.1)	4 (13.3)	10 (5.7)
Gender			
Male	12 (44.4)	6 (20.0)	44 (25.3)
Female	15 (55.6)	24 (80.0)	130 (74.7)
Education			
Secondary education	11 (40.7)	9 (30.0)	69 (32.4)
Tertiary study	14 (51.9)	19 (63.3)	75 (43.1)
Higher degree	2 (7.4)	2 (6.7)	29 (16.7)
Occupational category			
Manager/administrator	6 (22.2)	5 (16.7)	33 (19.0)
Professional/associate professional	3 (11.1)	10 (33.3)	47 (27.0)
Trades person	2 (7.4)	1 (3.3)	14 (8.0)
Clerical/sales/production & service	5 (18.5)	6 (20.0)	8 (4.6)
Home duties/retired	11 (40.7)	8 (26.7)	60 (34.4)
Employment Status			
Full time	10 (37.0)	8 (26.7)	65 (36.7)
Part time	2 (7.4)	2 (6.7)	22 (12.4)
Retired	11 (40.7)	18 (60.0)	80 (45.2)
Other (self employed/volunteer)	4 (14.8)	2 (6.7)	10 (5.6)
Marital status			
Married	20 (74.1)	22 (73.3)	144 (82.8)
Other	7 (25.9)	8 (26.7)	30 (17.2)
Relationship to person with dementia			
Spouse	4 (14.8)	8 (26.6)	48 (21.6)
Daughter	12 (44.4)	16 (53.3)	72 (41.4)
Son	10 (37.0)	4 (13.3)	23 (13.2)
Other relative	0	1 (3.3)	14 (8.0)
Other non relative	1 (3.8)	1 (3.3)	13 (7.5)
Generation			
Same generation	4 (14.8)	8 (26.6)	57 (32.7)
Younger generation	23 (85.2)	22 (73.4)	117 (67.3)
Ability to travel to Facility			
Yes	24 (88.9)	28 (93.3)	163 (93.6)
No	3 (11.1)	2 (6.7)	11 (6.4)
Length of time person with dementia in Facility			
Median (Range)	4 (1-72) months	21 (1-51) months	18 (1-129.6) months

* (Maas et al., 2000)

Characteristics of Residents with Dementia

All residents whose families participated in the study had a formal diagnosis of dementia as documented in their nursing care plan. The breakdown of the number of residents with dementia at the control site were SCU (n = 19), 67.9%, hostel (n = 7), 25.9% and nursing home (n = 2), 7.4%. At the intervention site the residents with dementia were SCU (n = 9), 33.3%, hostel (n = 12), 40.0% and nursing home (n = 8), 26.7%. There was a significant difference between the sites in the proportion of residents in the sample cared for in the SCU [$\chi^2(1) = 7.72, p = .005$]. The median length of time in residential care for residents with dementia at the control site was two years, with a range from 30 days to six years. At the intervention site the median length of time in residential care was one and three quarter years, with a range from one month to four and a quarter years. There was no statistically significant difference in the median length of time spent in residential care between the sites.

Families were asked to identify how long they believed their relative with dementia had experienced functional decline. The median length of functional decline identified by family caregivers at the control site was five and a quarter years, with a range from six months to ten years. At the intervention site the median length of functional decline was five years, with a range from one year to twelve years. There was no statistically significant difference in the median length of functional decline between the sites. All residents were identified by senior management at each facility as having irreversible dementia, confirmed by neuropsychological evaluation and medical diagnosis, and documented in their care plan. The majority of family caregivers were able to travel to the residential facility, representing (n = 24) 88.9% at the control site and (n = 28) 93.3% at the intervention site.

Extent of FIC Family Caregiver Involvement

As discussed in Chapter Three the extent of family caregiver involvement in the Maas et al. FIC intervention was measured by the sum of values for participation (intensity level), contact length, and frequency for all activities identified on the Family-Staff Partnership Agreement. In this study, a total of 29 formal partnership agreements

were completed at the intervention site, representing one for each resident whose family caregiver participated in the study. Two family caregivers shared the same agreement for their relative with dementia, resulting in 30 family caregiver participants. Consequently there is one less formal agreement compared to the number of family caregivers who participated in the surveys at the intervention site. The average dose of the intervention, as reflected in the partnership agreements, is 30.0, with a range from 3 to 72. The average number of activities contracted for by family caregivers was 3.9. The most frequently occurring activity required was physical activity (mean = 1.8), followed by psychosocial (mean = 1.1) and group activities (mean = 1.0). The most frequent physical activity requested was grooming (n = 11). The most frequent psychosocial activity was reminiscence (n = 7) and the most frequent group activity was social activities (n = 6). Details of participation level, contact length, frequency and specific activities are provided in Appendix F2. Table 5.2 provides a summary of the dosage and number of activities documented in the partnerships, and a comparison with the Maas et al study results. The median total dose and total number of activities identified in this study were very similar to those in the US study.

Table 5-2: Dosage and Number of Activities Documented in Family-Staff Partnerships

Australia	Mean (N=29)	SD	Range	Median
Total Dose	30.0	17.7	3-72	31
Total number of activities	3.9	1.9	2-10	4
No of group activities	1.0	0.9	0-3	1
No of physical activities	1.8	1.7	0-6	2
No of psycho-social activities	1.1	0.7	0-3	1
US	Mean (N=74)	SD	Range	Median
Total Dose	36.0	15.4	8-85	35
Total no of activities	4.4	1.9	1-9	4
No of group activities	0.3	0.6	0-3	0
No of physical activities	1.5	0.9	0-3	1
No of psychosocial activities	2.5	1.6	0-6	2

The following section presents the family caregiver pre and post-intervention findings, as discussed within the four caregiver outcome clusters.

Family Caregiver Pre and Post-Intervention Findings

This section presents the family caregiver findings from the self-report questionnaires, as stated in the hypotheses in Chapter Two. The outcome clusters of closely related items used in the Maas et al research were adopted in this study and are summarised in Table 3.1. Firstly, the findings related to differences in family caregiver *knowledge* of dementia pre and post-intervention are presented. The stress and satisfaction findings within each outcome cluster are then presented as they relate to each caregiver area. The relationships between the outcome measures, caregiver areas and instruments are summarised in Table 5.3 below. The table also includes a summary of the expected changes in stress and satisfaction measures, as stated in the hypotheses in Chapter Two.

Table 5-3: Family Caregiver Areas, Instruments and Outcome Cluster Measures

Family Caregiver Area	Instrument	Measure	Hypothesised Expected Change
Emotional reaction to care recipient (<i>Guilt, Captivity, Loss</i>)	FPCR	Stress	Reduced
Perceived Relationship with staff (<i>Conflict</i>)	FPCR	Stress	Reduced
(<i>Consideration</i>)	FPCT	Satisfaction	Improved
Perceptions of care (<i>Physical care, Activities</i>)	FPCT	Satisfaction	Improved
Perceptions of management (<i>Management effectiveness</i>)	FPCT	Satisfaction	Improved

Family Caregiver Knowledge of Dementia

Hypothesis 1 stated that there will be an improvement in family caregiver *knowledge* for those who participate in the FIC intervention compared to those who do not.

Changes in family caregiver *knowledge* were tested by using the FKDT at Time 1 and Time 2, pre and post the intervention. The results from the independent samples t-test analysis identified that there was no significant difference in dementia *knowledge*

between the control and intervention sites both pre and post-intervention. The paired samples t-test used to examine whether there were any significant differences in the FKDT scores from Time 1 to Time 2 indicated a significant increase in *knowledge* for families at the intervention site [$t(29) = -4.052, p < .001$], but not at the control site [$t(26) = -1.924, p > .05$]. Thus, Hypothesis 1, that there will be an improvement in *knowledge* for those who participate in the intervention compared to those who do not, is supported. The FKDT scores are summarised in Table 5.4, below.

Table 5-4: FKDT Pre and Post-Intervention Scores

Pre-Test FKDT Scores		Post-Test FKDT Scores	
Control	Intervention	Control	Intervention
Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
15.07 (1.49)	15.17 (2.39)	15.85 (2.38)	16.53 (2.76)

The next section presents the findings in relation to family caregiver stress.

Family Caregiver Stress

Hypothesis 1 also stated that there will be a reduction in family caregiver stress for those who participate in the FIC intervention compared to those who do not. Family caregiver stress was measured pre and post-intervention by the FPCR seven point Likert (1= disagree to 7 = agree) instrument in the caregiver areas of ‘emotional reaction to care recipient’ and ‘perceived relationship with staff’ (see Table 5.3). The FPCR parallels the items of the SPCR staff instrument and specifically measures the degree of stress experienced by family members involved in the care of their relative with dementia, particularly in the subscale *conflict* with staff (Maas et al., 2000).

Emotional Reaction to Care Recipient

At baseline (Time 1) there were no significant differences between the control and intervention sites in the subscale measures for families’ ‘emotional reaction to the care recipient’ (*guilt, captivity, loss*). Similarly, there were no significant differences between the sites at Times 2, 3 and 4. From Time 1 to Time 2 there was a significant decrease in family stress levels at the control site for the subscale *captivity* [$t(26) = 2.11, p < .05$], which reflected a decrease in stress from the obligations of caregiving. However, this difference was not detected at Time 3 or Time 4. There were no other statistically significant changes identified in the *guilt, captivity* or *loss* subscale measures at the control site, or the intervention site from Time 1 to Time 4.

A summary of the subscale means and standard deviations from Time 1 to Time 4 for these subscales is presented in Table 5.5.

Perceived Relationship with Staff (*Stress*)

When examining family caregiver stress in relation to their ‘perceived relationship with staff’ (subscale measure *conflict*) there were no significant site differences identified at Time 1 or Time 2. However, at Time 3 significant differences were identified between the two sites for the *conflict* with staff subscale [$t(55) = -2.53, p < .05$], reflecting an increase in family caregivers’ stress in relation to their perceived relationship with staff at the intervention site. Similarly at Time 4, significant differences between the two sites for the *conflict* with staff subscale were detected [$t(55) = -2.36, p < .05$]. There were no other statistically significant changes identified in the *conflict* subscale measure at the control site, or the intervention site from Time 1 to Time 4. A summary of the subscale means and standard deviations from Time 1 to Time 4 for this subscale is presented in Table 5.5 below. The findings from the paired samples and within samples t-tests are presented in Tables 5.7 and 5.8.

Table 5-5: Family Caregiver Stress - Summary of Means Time 1 to Time 4

Measure	Control				Intervention			
	MT1 (SD)	MT2 (SD)	MT3 (SD)	MT4(SD)	MT1(SD)	MT2(SD)	MT3(SD)	MT4(SD)
Emotional reaction to care recipient								
Guilt	2.50(1.33)	2.53(1.25)	2.66(1.29)	2.58(1.27)	2.60(1.24)	2.57(1.32)	2.69(1.20)	2.58(1.13)
Captivity	3.18(1.36)	2.91(1.17)	3.00(1.18)	2.90(1.24)	3.32(1.26)	3.22(1.36)	3.34(1.26)	3.36(1.31)
Loss	4.62(1.33)	4.60(0.96)	4.62(0.95)	4.63(0.97)	4.32(1.35)	4.26(1.03)	4.33(1.07)	4.36(1.03)
Perceived Relationship with staff								
Conflict	2.90(0.84)	2.90(0.87)	2.39(1.29)	2.43(0.91)	3.50(1.22)	3.50(1.20)	3.17(0.95)	3.14(1.31)
Consideration	5.53(1.69)	5.46(0.82)	5.50(0.79)	5.46(0.77)	5.31(1.19)	5.14(1.22)	4.88(0.84)	4.92(1.25)

The conclusion from the findings for the subscales that measure stress is that Hypothesis 1, family caregiver stress will be reduced at the intervention site compared to the control site, is not supported.

Family Caregiver Satisfaction

Hypothesis 1 stated that there will be an improvement in family caregiver satisfaction for those who participate in the FIC intervention compared to those who do not.

Family caregiver satisfaction was measured pre and post-intervention by the FPCT

seven point Likert scale (1 = disagree to 7 = agree) instrument in the caregiver areas of ‘perceived relationship with staff’, ‘perceptions of care’ and ‘perceptions of management’ (see Table 5.3).

Perceived Relationship with Staff (*Satisfaction*)

For the FPCT ‘perceived relationship with staff’ subscale (*consideration* of the family and the resident) there were no significant site differences in family caregiver satisfaction at Time 1 or Time 2. However, at Time 3 significant differences were detected between the two sites [$t(55) = 2.18, p < .05$], reflecting decreased satisfaction at the intervention site. This finding was supported by the paired samples t-test which also identified the decreased satisfaction at the intervention site from Time 1 to Time 3 [$t(29) = 2.47, p < .05$], and from Time 1 to Time 4 [$t(29) = 2.14, p < .05$]. A summary of the subscale means and standard deviations from Time 1 to Time 4 for this subscale is presented in Table 5.6.

Perceptions of Care

For the two ‘perceptions of care’ subscales (*physical care* and *activities*) one statistically significant difference at baseline was detected between the two sites for family perceptions with respect to (psychosocial) *activities* [$t(55) = 2.01, p < .05$]. This finding represented a higher level of family caregiver satisfaction at the control site prior to the intervention. A one-way between groups analysis of covariance was conducted to compare the site means and control statistically for confounding variables. All participants’ scores on the pre-intervention FPCT *activities* cluster were used as the covariate. After controlling for site differences in pre-intervention mean scores, the analysis showed that there was no significant difference between the post-intervention scores for the subscale *activities* (Polit & Beck, 2008).

A significant difference was detected again at Time 2 for the subscale *activities* [$t(55) = 2.62, p < .05$], representing an improvement in satisfaction with psychosocial *activities* at the control site and no change at the intervention site. The site differences in satisfaction with *activities* continued to increase at Time 3 [$t(55) = 2.96, p < .01$] and at Time 4 [$t(55) = 2.73, p < .001$]. At Time 2 significant site differences were also identified for the *physical care* subscale, [$t(55) = 2.10, p < .05$], reflecting an improvement in satisfaction with *physical care* at the control site and a deterioration in satisfaction at the intervention site. There were no significant site differences for

satisfaction with *physical care* at Time 3 or Time 4. A summary of the subscale means and standard deviations from Time 1 to Time 4 for these subscales is presented in Table 5.6.

The ‘perceptions of care’ within subjects analysis identified one significant difference for *physical care* at the control site from Time 1 to Time 2 [$t(26) = -1.99, p < .05$], representing an improvement in satisfaction. There were no other statistically significant changes identified in the *physical care* or *activities* subscale measures at the control site, or the intervention site from Time 1 to Time 4. Further exploration of item responses highlighted the areas in which changes in satisfaction with care occurred at both sites from Time 1 to Time 4. At the intervention site there were some concerns from Time 3 to Time 4 with medication management. At the control site family caregiver satisfaction improved with respect to aspects of *physical care* and sensory stimulation.

Perceptions of Management

For the caregiver area ‘perceptions of management’ there were no significant site differences identified for the subscale *management effectiveness* at Time 1. At Time 2 a significant difference between the sites was detected [$t(55) = 2.21, p < .05$], reflecting a decrease in satisfaction at the intervention site.

From Time 1 to Time 2, paired samples analysis detected a significant difference in measurement of *management effectiveness* at the intervention site [$t(29) = 2.87, p < .05$], reflecting a decrease in family caregiver satisfaction. The decreasing levels of satisfaction with management continued from Time 1 to Time 3, both at the control site [$t(26) = 2.87, p < .05$] and the intervention site [$t(29) = 2.65, p < .05$]. The results from Time 1 to Time 4 also found a continuing level of dissatisfaction from families at the intervention site [$t(29) = 2.24, p < .05$]. A summary of the subscale means and standard deviations from Time 1 to Time 4 for these subscales is presented in Table 5.6.

Table 5-6: Family Caregiver Satisfaction - Summary of Means Time 1 to Time 4

Measure	Control				Intervention			
	MT1 (SD)	MT2 (SD)	MT3 (SD)	MT4(SD)	MT1(SD)	MT2(SD)	MT3(SD)	MT4(SD)
Perceptions of care								
Physical care	5.09(1.27)	5.45(1.01)	5.35(1.36)	5.25(1.39)	4.97(1.47)	4.76(1.41)	4.80(1.43)	4.81(1.41)
Activities	4.90(0.90)	5.04(0.76)	5.00(0.73)	4.98(0.64)	4.18(1.64)	4.17(1.58)	3.99(1.63)	4.13(1.49)
Perceptions of Management								
Management effectiveness	4.79(0.75)	4.79(0.85)	4.73(0.87)	4.78(0.81)	4.65(1.20)	4.20(1.11)	4.32(0.99)	4.33(1.10)

There were no within subject item differences detected at the control site from Time 1 to Time 4. Further exploration of mean item responses revealed that at the intervention site there was a significant reduction in satisfaction with *management effectiveness* in relation to personal belongings from Time 1 to Time 2. From Time 1 to Time 4 families were significantly less satisfied with the way their family member was treated.

The findings from the paired samples and within samples t-tests are presented in Tables 5.7 and 5.8. The findings reveal that the significant positive effects for family caregivers occurred at the control site at Time 2 for the subscales *captivity* and *physical care*. At the intervention site the level of family caregiver satisfaction decreased at Time 3 and Time 4 in the subscale *staff consideration*. Similarly, satisfaction with *management effectiveness* decreased at the intervention site at Time 2, and continued to Time 3 and Time 4. There was also a significant decrease in *management effectiveness* detected at Time 3 at the control site.

Hence the conclusion from the findings for the subscales that measure family caregiver satisfaction is that Hypothesis 1, family caregiver satisfaction will improve at the intervention site compared to the control site, is not supported.

Summary of Family Caregiver Quantitative Findings

The family caregiver results presented clearly show the positive intervention effects of knowledge of dementia. However, positive intervention effects in terms of stress and

satisfaction were limited. The following tables summarise the between subject site differences for each of the family caregiver subscales, and supports the discussion of each caregiver area through the identification of significant differences. The negative between site differences were identified for *conflict*, *consideration*, *physical care*, *activities* and *management effectiveness*. Differences in family caregiver stress associated with their ‘perceived relationship with staff’ increased in significance at Time 3 and Time 4 for the subscale *conflict*, and at Time 3 family caregiver satisfaction for the subscale *consideration*. Family caregiver satisfaction in the subscale *physical care* was consistently higher at the control site, and consistently higher at Time 3. Similarly, for the subscale *activities*, satisfaction was significantly higher at the control site at all Time phases. Family *knowledge* of dementia was higher at the intervention site than at the control site.

Table 5-7: Summary of Family Member Between Subject Independent Samples

Measure	Time 1	Time 2	Time 3	Time 4
Emotional reaction to care recipient	t (55)	t (55)	t(55)	T (55)
Guilt	-0.28	-0.13	-0.06	0.02
Captivity	-0.39	-0.96	-1.15	-1.34
Loss	0.92	1.09	0.99	1.03
Perceived Relationship with staff				
Conflict	-1.78	-1.95	-2.53*	-2.36*
Consideration	-0.12	-1.14	-2.18*	-1.94
Perceptions of care				
Physical care	0.33	2.10*	1.49	1.18
Activities	2.01*	2.62*	2.96**	2.73**
Perceptions of management				
Management effectiveness	0.88	2.21*	1.64	1.71
Family knowledge of dementia	-0.17	-0.99		

*p<.05 **p<.01

Table 5.8 on the following page presents the within site differences at the control and the intervention site from Time 1 to Time 4.

Table 5-8: Summary of Family Paired Samples t-test Baseline to Time 4 Across all Time Settings

Measure	Control							Intervention						
	Mean t ₁	Mean t ₂	t(26)	Mean t ₃	t(26)	Mean t ₄	t(26)	Mean t ₁	Mean t ₂	t(29)	Mean t ₃	t(29)	Mean t ₄	t(29)
Emotional reaction to care recipient														
Guilt	2.50	2.53	-0.21	2.66	-0.87	2.58	-0.43	2.60	2.57	0.28	2.69	-0.39	2.58	0.09
Captivity	3.18	2.91	2.12*	3.00	1.25`	2.90	1.43	3.32	3.22	0.79	3.34	-0.13	3.36	-0.20
Loss	4.62	4.60	0.10	4.62	0.00	4.63	-0.11	4.32	4.26	0.83	4.33	-0.13	4.36	-0.18
Perceived Relationship with staff														
Conflict	2.90	2.90	-0.06	2.39	1.38	2.43	1.21	3.50	3.50	-0.29	3.17	-0.35	3.14	-0.16
Consideration	5.53	5.46	-1.48	5.50	-1.67	5.46	-1.60	5.31	5.14	1.69	4.88	2.65*	4.92	2.14*
Perceptions of care														
Physical care	5.09	5.45	-1.99*	5.35	-1.78	5.25	-1.14	4.97	4.76	0.93	4.80	0.88	4.81	0.82
Activities	4.90	5.04	-1.10	5.00	-0.67	4.98	-0.61	4.18	4.17	0.07	3.99	0.98	4.13	0.24
Perceptions of management														
Management effectiveness	4.79	4.79	1.84	4.73	2.17*	4.78	1.98	4.65	4.20	2.86**	4.32	2.47*	4.33	2.24*
Family knowledge of dementia														
	15.07	15.85	-1.92					15.17	16.53	-4.05***				

*p <.05 **p<.01***p<.001

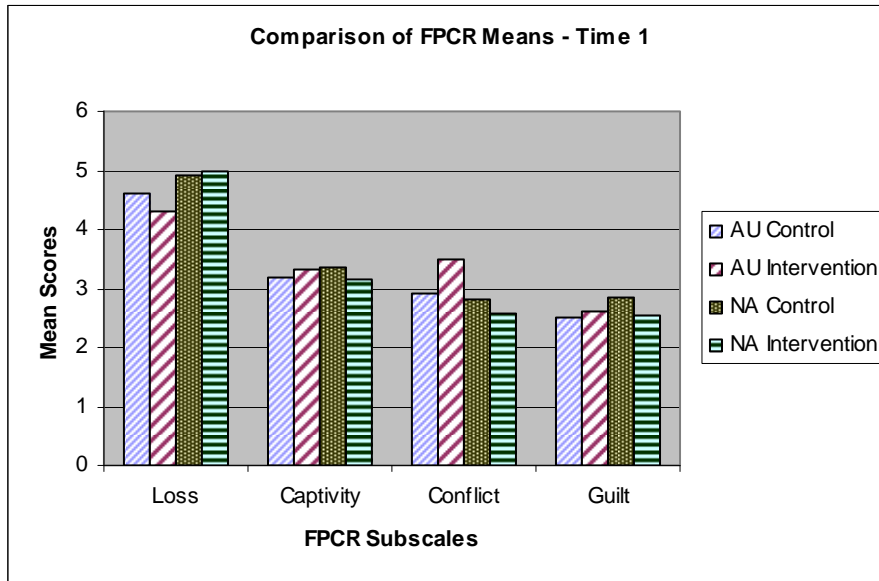
Descriptive Site Comparison of Family Measures: Australia and US

The descriptive analysis of mean score comparisons across our two sites and with the Maas et al. study results at Time 1 and Time 2 is presented to compare and contrast any major cross-cultural differences in the stress and satisfaction subscale findings. Please note that the Maas et al. study data were only available for Time 1 and Time 2.

FPCR Subscale Comparisons

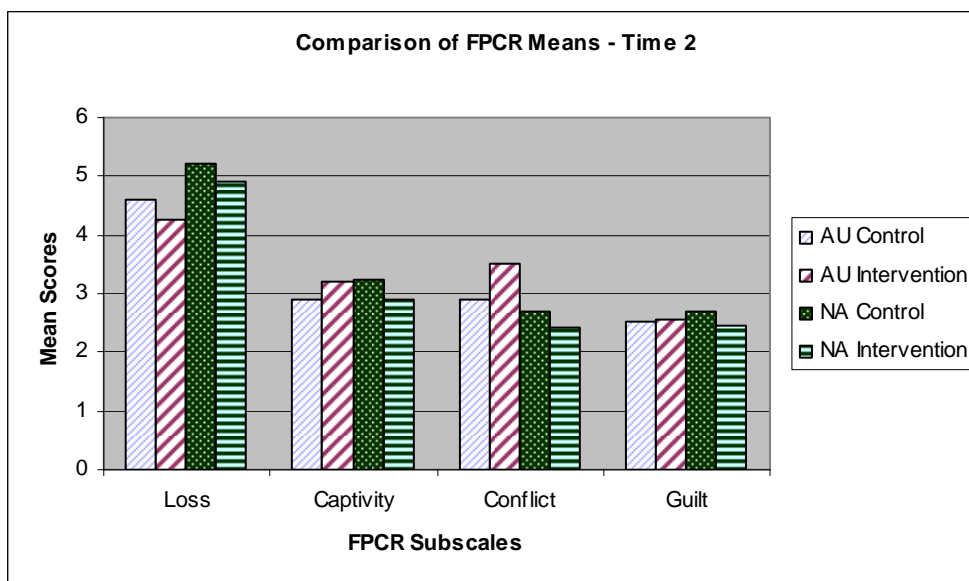
Pre-intervention at Time 1 mean scores on the FPCR subscales measuring stress levels for family caregivers presented a similar picture at both the control and intervention sites. For the control site the highest (worst) stress score was for *loss* of the positive relationship with the care recipient (M = 4.62), followed by feelings of *captivity* (M = 3.18), *conflict* with staff (M = 2.90), and *guilt* (M = 2.50) having the lowest scores. The intervention site's scores presented a similar picture for *loss* (M = 4.32), but revealed a higher score than the control site for *conflict* (M = 3.50), followed by *captivity* (M = 3.32) and *guilt* (M = 2.60). The subscale mean score measures also followed a similar pattern to the Maas et al. mean scores (please note that separate scores for the Maas et al control and intervention sites were not available). The pattern of the Maas et al. scores were *loss* (M = 4.74), followed by *captivity* (M = 3.14), *conflict* (M = 2.68) and *guilt* (M = 2.68). Figure 5.1 summarises the comparison of the FPCR subscales at Time 1 between the two sites in this study, as well as with the Maas et al. mean scores within each subscale.

Figure 5-1: Comparison of FPCR Means at Time 1



It is clear from Figure 5.1 that although there were no significant differences identified for the *conflict* subscale between this study control and the intervention site, the descriptive comparison illuminates a persistently higher stress score at the Australian intervention site. Figure 5.2 below summarises the comparison of the FPCR subscales at Time 2 between the two sites in this study, as well as with the Maas et al. mean scores within each subscale.

Figure 5-2: Comparison of FPCR Means at Time 2

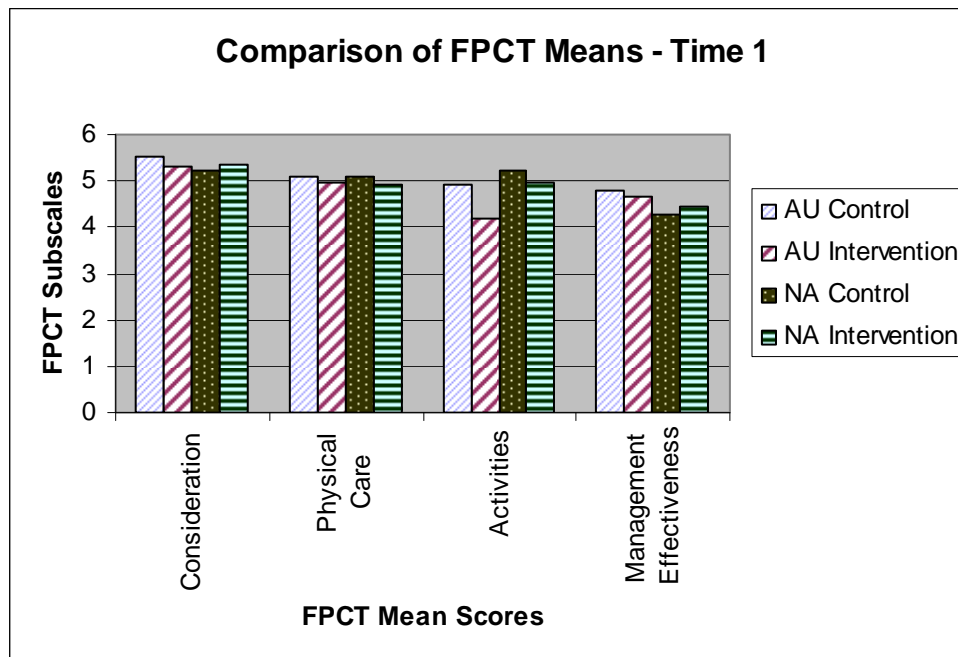


The higher score for *conflict* with staff was also evident in the Time 2 post-intervention mean scores comparison of the FPCR subscales measuring stress levels for family caregivers. At the intervention site, post-test scores also followed a similar pattern to its pre-test scores, with *loss* ($M = 4.26$) scoring highest, then *conflict* ($M = 3.5$), *captivity* ($M = 3.22$) and *guilt* ($M = 2.57$) scoring lowest. There was a significant difference at the control site between the pre-test and post-test *captivity* subscale ($t(26) = 2.12, p = .04$), representing an improvement in perceived restrictions imposed by family members' obligations to provide care. For the FPCR measures the post-test (Time 2) scores at the intervention site show minimal 'intervention effect', with a slight reduction in family members' sense of *loss*, *guilt* and *captivity*, and no change in *conflict* with staff. Hence the level of family stress related to *conflict* with staff remains high at this intervention site compared to the Maas et al. mean scores.

FPCT Subscale Comparisons

At baseline the control site family members' scores on the FPCT were most positive on the *consideration* scale ($M = 5.53$; scale = 1 to 7), and least positive on the *management effectiveness* subscale ($M = 4.79$), with scores for *physical care* ($M = 5.09$) and *activities* ($M = 4.90$) falling between highest and lowest. The trend was somewhat similar at the intervention site, with *consideration* ($M = 5.31$) scoring highest, followed by *physical care* ($M = 4.97$), *management effectiveness* ($M = 4.65$), and *activities* ($M = 4.18$) scoring lowest. The comparison between the Maas et al. and Australian sites illuminates the lower satisfaction score at the Australian intervention site for the subscale *activities* compared to the control site and the Maas et al. study sites. Figure 5.3 summarises the descriptive statistics for the baseline subscale scores of the FPCT, as well as a cross-cultural comparison with the Maas et al. study results.

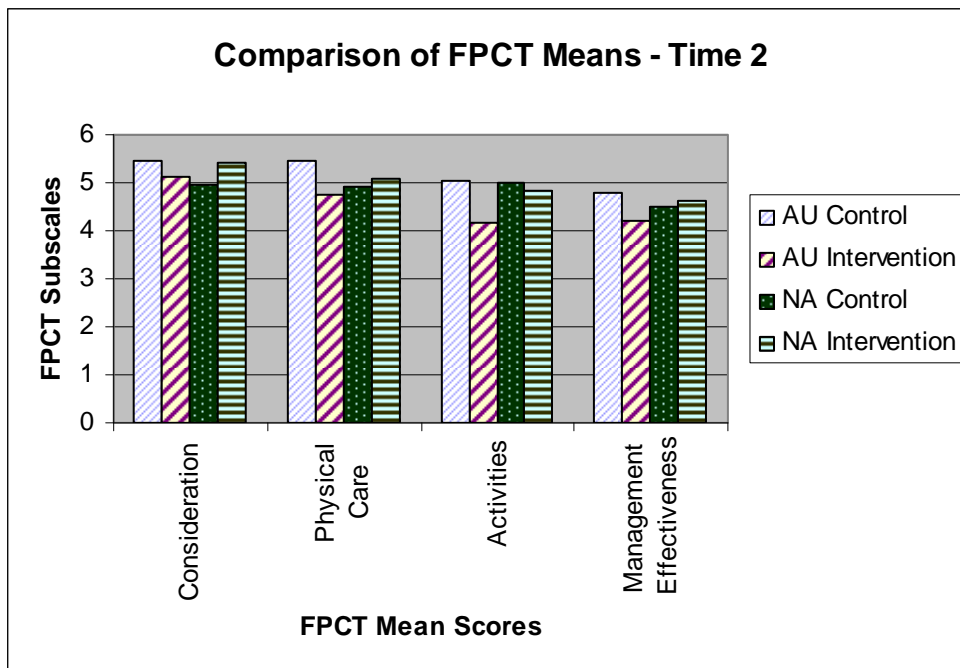
Figure 5-3: Comparison of FPCT Means at Time 1



For the control site in this study at Time 2, the post-intervention satisfaction scores on the FPCT followed a similar pattern to the baseline scores, with *consideration* scoring the most highly ($M = 5.46$), *management effectiveness* the least positive ($M = 4.79$), and *physical care* ($M = 5.45$) and *activities* ($M = 5.04$) scoring in between. The FPCT scores for the intervention site reflected a similar pattern to the baseline data, with *consideration* ($M = 5.14$) scoring highest, followed by *physical care* ($M = 4.76$), *management effectiveness* ($M = 4.20$) and *activities* ($M = 4.17$) once again the lowest score. The lower satisfaction scores were also evident at the intervention site for the four subscales in the Time 2 post-intervention mean scores comparison of the FPCT subscales.

Figure 5.4 summarises the means and standard deviations for the Time 2 scores of the FPCT, as well as a cross-cultural comparison with the Maas et al. study results.

Figure 5-4: Comparison of FPCT Means at Time 2



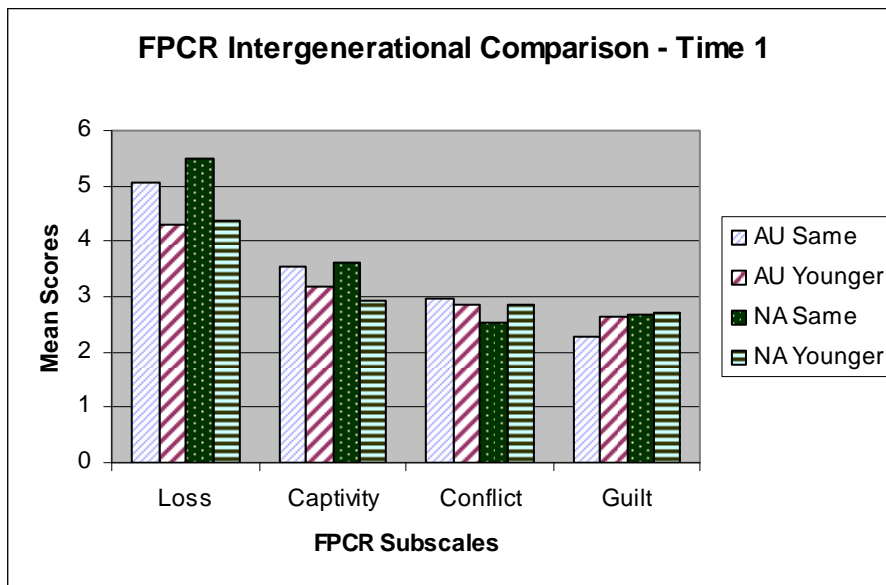
The following section presents an intergenerational comparison of the FPCR stress scores within each subscale at Time 1 and Time 2.

Family Caregiver Generation Comparison

The family caregiver generation comparison is presented for the total samples (control and intervention) to highlight differences in stress scores at Time 1 and Time 2.

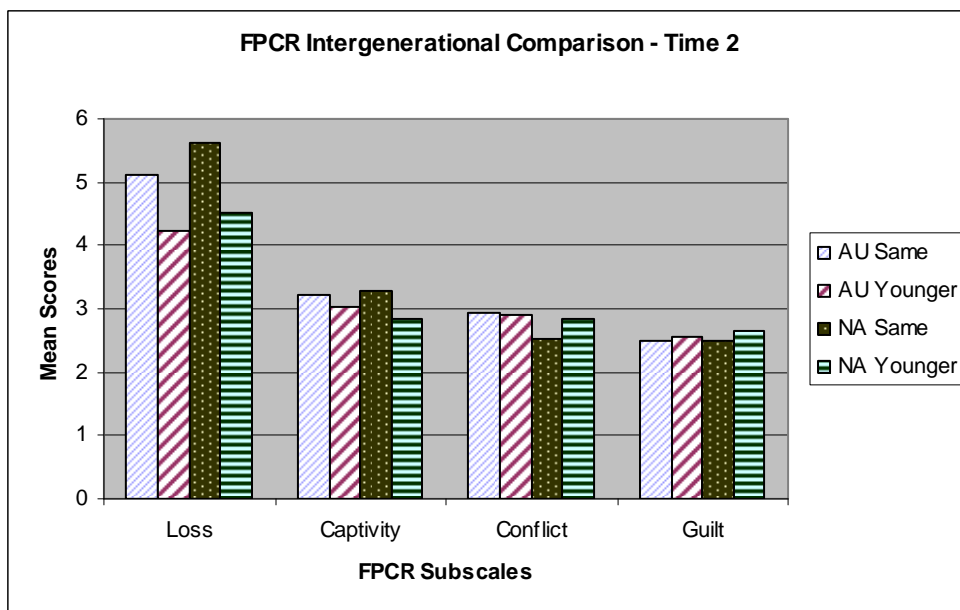
Figure 5.5 illuminates at each site the lower stress levels associated with the subscale loss for the younger generation compared to the same generation at Time 1.

Figure 5-5: FPCR Intergenerational Comparison at Time 1



In the Maas et al. study there was a significant reduction in stress levels for same generation family caregivers at the intervention site for the subscale *loss* at Time 2 (5.58 to 5.29). However, the increase in the *loss* scores at the Maas et al. control site (5.39 to 5.94) has the opposite effect, resulting in a similar result to Time 1. Figure 5.6 below highlights the slightly lower score at the Australian sites for the same generation in the subscale *loss*, compared to the Maas et al. study results at Time 2.

Figure 5-6: FPCR Intergenerational Comparison at Time 2



The results of the FPCR intergenerational comparison will be further discussed in Chapter eight.

Conclusions

The descriptive analyses of the family caregiver stress measures reveal that at the intervention site, at Time 1 and Time 2, there were consistently higher stress levels for the subscales *loss*, *captivity*, *guilt* and *conflict* with staff. Alternatively there was less stress associated with staff *conflict* in the Maas et al. study than at either of the Australian study sites. Descriptive analyses of family caregiver satisfaction reveal that at Time 1 and Time 2 family satisfaction scores in the subscales *consideration*, *physical care*, *activities* and *management effectiveness* were consistently lower at the intervention site compared to the control site. The satisfaction scores at the intervention site were also lower than the Maas et al. study scores.

The following chapter presents the staff caregiver pre and post-intervention findings.

CHAPTER 6

STAFF CAREGIVER PRE AND POST-INTERVENTION QUANTITATIVE FINDINGS

Introduction

This chapter presents the quantitative findings from the analysis of the staff caregiver outcomes, as measured by the FIC staff instruments described in detail in Chapter Three. This chapter firstly aims to describe the demographic and caregiver characteristics of the staff sample and to compare the control site and intervention site at baseline (Time 1). Secondly, the pre-intervention and post-intervention within subject and between subjects ANOVA's are presented as guided by the hypotheses identified in Chapter Two for Time 2, Time 3 and Time 4. Thirdly a descriptive analysis of mean score comparisons across the sites and with the Maas et al. study findings at Time 1 and Time 2 is presented to ascertain the presence of cross cultural differences.

Site Comparison of Demographic and Caregiver Characteristics

A total of 58 staff members agreed to participate in the study, comprising 27 from the control site and 31 from the intervention site. Of these (n = 25) 92.6 % were female at the control site and (n = 27) 87.1% at the intervention site. At each site there was a similar majority of staff members who were born in another country, with (n = 16) 59.2% at the control site and (n = 16) 51.6% at the intervention site. The minority of Australian born staff members therefore was also similar at each site. The average age of staff at the control site (41.2 years) resembled that of the intervention site (39.8 years), as did the average number of years in their occupation (10.6 years compared to 9.2 years respectively). There was a significant difference [$\chi^2(1) = 7.10, p = .008$] between the proportion of those who were married at the control site (n = 23), 85.2% compared to the intervention site (n = 15), 48.4%. The majority of staff had less than

three children (n = 16, 59.3% and n = 23, 74.2% respectively) and less than three children at home (n = 23, 85.1% and n = 28, 90.4% respectively).

The main area of work for staff participants at the control and intervention sites was the SCU (n = 10, 37.0% and n = 10, 25.8% respectively), nursing home (n = 8, 29.6% and n = 8, 32.3% respectively), hostel (n = 6, 22.2% and n = 7, 22.6% respectively) and all areas (n = 3, 11.1% and n = 6, 19.4% respectively). Although the percentage of participant RNs was similar for the two sites (n = 7, 25.9% compared to n = 7, 22.6% respectively) the percentage of EENs at the control site (n = 4, 14.8%) was larger than at the intervention site (n = 2, 6.5%). Alternatively the percentage of Personal Care Workers (PCWs) at the control site (n = 14, 51.8%) was less than at the intervention site (n = 21, 67.7%), with two Diversional Therapists (DTs) (n = 2, 7.5%) at the control site and one DT (n = 1, 3.2%) at the intervention site. Staff had worked an average number of 36 months at the control site and 50 months at the intervention site. Most staff worked part time (n = 18, 66.7% at the control site and n = 20, 64.5% at the intervention site). There was a smaller percentage of casual staff at the control site (n = 1, 3.7%), compared to the intervention site (n = 5, 16.1%), and more full time staff (n = 8, 29.6% compared to n = 6, 19.4% respectively). Chi squared tests showed that these differences were not statistically significant.

In summary, the staff demographic and caregiver characteristics for each site were not significantly different, with the exception of the proportion of those who were married at the control site, compared to the intervention site. A summary of demographic and caregiver characteristics is shown in Table 6.1. Included in the summary are the staff caregiver characteristics of the Maas et al. study sample. The sample comparisons will be examined further in Chapter Eight.

Table 6-1: Summary of Staff Caregiver Demographic Characteristics

Demographic Characteristic	Control Group (N=27)		Intervention Group (N=31)		NA* (N=597)	
	n	(%)	n	(%)	n	(%)
Gender						
Male	2	(7.4)	4	(12.9)	36	(7.0)
Female	25	(92.6)	27	(87.1)	550	(93.0)
Age						
Mean (SD)	41.2	(8.4)	39.8	(8.5)	35	(12.3)
Median (Range)	41.0	(29-54)	38.0	(22-56)	34	(17-72)
Number of years in occupation						
Mean (SD)	10.6	(9.3)	9.2	(8.5)	8.6	(9.2)
Median (Range)	5.0	(0.5-32.0)	7.0	(0.6-32.0)	5.0	(1-40)
Number of years at facility						
Mean (SD)	3.0	(1.5)	4.2	(3.4)	3.5	(4.9)
Median (Range)	3.0	(0.5-5.0)	4.0	(0.5-12.0)	1.4	(0.1-28)
Education						
Some high school	3	(11.1)	5	(16.1)	21	(3.5)
High school	15	(55.6)	15	(48.4)	195	(32.8)
Some University	4	(14.8)	4	(12.9)	313	(52.4)
University	3	(11.1)	4	(12.9)	40	(6.7)
Graduate degree	1	(3.7)	3	(9.7)	12	(2.0)
Other	1	(3.7)	0	(0)	13	(2.2)
Occupational category						
Registered Nurse	7	(25.9)	7	(22.6)	106	(17.8)
Enrolled Nurse	4	(14.8)	2	(6.5)	85	(14.2)
PCW/AIN	14	(51.8)	21	(67.7)	406	(68.0)
Diversional Therapist	2	(7.5)	1	(3.2)	0	0
Employment status						
Full time	8	(29.6)	6	(19.4)	355	(59.6)
Part time	18	(66.7)	20	(64.5)	149	(25.0)
Casual	1	(3.7)	5	(16.1)	92	(15.4)
Marital status						
Married	23	(85.2)	15	(48.4)	309	(52.0)
Other	4	(14.8)	16	(51.6)	287	(48.0)

* (Maas et al., 2000)

Staff Member Pre and Post-Intervention Findings

As with the family measures, the staff outcome clusters of closely related items used in the Maas et al. study were adopted in this study and are summarised in Table 3.1. Firstly, the findings for differences in staff caregiver knowledge pre and post-intervention are presented. The findings for each outcome cluster are then presented as they relate to each caregiver area. The relationships between the outcome measures, caregiver areas and instruments are summarised in Table 6.2 below. The table also includes a summary of expected changes in staff caregiver stress, job satisfaction and attitudes to family measures, as stated in Hypothesis 2 in Chapter Two.

Table 6-2: Staff Caregiver Areas, Instruments and Outcome Cluster Measures

Staff Caregiver Area	Instrument	Measure	Hypothesised Expected Change
Emotional reaction to care recipient (<i>Inappropriate behaviour, Aggression</i>)	CSI	Stress related to person with dementia	Reduced
Perceived relationship with family (<i>Exclusion, Dominion</i>)	SPCR	Stress	Reduced
(<i>Partnership, Disruption Relevance</i>)	AFC	Attitude to families (job satisfaction)	Improved
Perceptions of caregiving (<i>Resident harm (safety), Task Burden, Role Inadequacy</i>)	CSI	Stress	Reduced
	SPCR	Stress	Reduced
Perceived organizational support (<i>Resource (deficiency)</i>)	CSI	Stress related to job satisfaction	Reduced

Staff Caregiver Knowledge of Dementia

Hypothesis 2 states that there will be an improvement in staff caregiver *knowledge* for those who participate in the FIC intervention compared to those who do not. Changes in staff caregiver *knowledge* were tested by using the KDT at Time 1 and Time 2, pre and post the intervention. The between subjects independent *t*-test identified no significant differences between the control site and the intervention site either pre or post-intervention. The within subjects analysis detected some improvement in *knowledge* from Time 1 to Time 2 at both the intervention site and the control site, but these changes were not statistically significant. The results of the test showed a reasonably high *knowledge* of dementia at both sites, as summarised in the following table.

Table 6-3: KDT Pre and Post-Intervention Scores*

Pre-Intervention FKDT Scores		Post-Intervention FKDT Scores	
Control Mean (SD)	Intervention Mean (SD)	Control Mean (SD)	Intervention Mean (SD)
24.85 (2.52)	26.10 (2.65)	25.89 (2.56)	26.45 (2.11)

* Maximum score = 33

Although there has been an improvement in dementia knowledge at both sites, this is not significant and therefore Hypothesis 2, staff caregivers will have improved knowledge, is not supported. The next section presents the findings in relation to staff caregiver stress from caring for the person with dementia.

Staff Caregiver Stress

Hypothesis 2 also states that there will be a reduction in staff caregiver stress for those who participate in the FIC intervention compared to those who do not. Staff caregiver stress was measured by the CSI seven point Likert scale (1 = not stressful to 7 = very stressful) instrument in the caregiver area of ‘emotional reaction to care recipient’ (see Table 6.2).

Emotional Reaction to Care Recipient

At Time 1 there were no significant differences between the control site and intervention site for the 'emotional reaction to care recipient' subscale measures (*inappropriate behaviour* and *aggression*). There were also no significant site differences for either of the subscale measures post-intervention at Time 2, Time 3 and Time 4.

The within subject analysis revealed a significant difference in the *inappropriate behaviour* subscale from Time 1 to Time 3 at the intervention site [$t(30) = -2.10, p < .05$], representing an increase in staff stress post-intervention. As with Time 3 there was also a significant difference from Time 1 to Time 4 [$t(30) = -2.09, p < .05$], representing a continued increase in staff stress at the intervention site for the subscale *inappropriate behaviour* from residents.

Further exploration of the subscale items for *inappropriate behaviour* highlighted that of the 17 items within this subscale there were eight particular areas of concern at the intervention site causing increased staff stress. These items are presented in Table 6.4. No increases in staff stress levels were found with respect to *aggressive behaviour* from residents from Time 1 to Time 4 at either the control or the intervention site. Table 6.4 presents a summary of the within site mean changes and standard deviation scores for staff caregiver stress in relation to *inappropriate behaviour* at the intervention site from Time 1 to Time 4.

Table 6-4: Intervention Site - CSI Items – Emotional Reaction to Care Recipient

Questionnaire Item	T1 to T3	T1 to T4	T2 to T3	T2 to T4
Inappropriate Behaviour	M D (SD)	M D (SD)	M D (SD)	M D (SD)
5. Some residents rummage through or use staff belongings (eg uses staff rest room).	-0.77 (1.65)**	-0.74 (1.61)**	-0.61 (1.72)**	-0.58 (1.68)*
6. Some residents keep trying to go home or each day think they are going home.		-0.71 (1.98)*		-0.48 (1.91)*
18. Stressful when residents talk constantly.			-0.55 (1.51)*	-0.49 (1.85)*
19. Stressful when residents curse me when I am delivering their care.	-0.64 (1.73)*	-0.94 (1.66)**	-0.45 (1.73)*	
25. Stressful when residents will not stay in bed at night.	-0.88 (1.58)**			
27. Stressful when a great deal of time and attention are required to complete simple tasks.			-0.51 (1.74)*	-0.51 (1.82)*
31. When residents put their possessions in inappropriate places (eg toilet, waste basket).	-0.84 (1.52)**	-0.90 (1.57)**		
34. Stressful when residents will not stay in chairs or bed.				-0.58 (1.86)*

MD = Mean Difference, SD = Standard Deviation

*p<.05, **p<.01, ***p<.001

In summary, the findings do not support the hypothesis that staff stress in relation to their emotional reaction to the care recipient would reduce at the intervention site, compared to the control site. The following section presents the findings in relation to staff attitudes towards family caregivers.

Staff attitudes towards family caregivers

Hypothesis 2 also stated that there would be an improvement in job satisfaction, reflected in staff attitudes towards families for those who participate in the FIC intervention compared to those who do not. Staff attitudes to family members were measured by the SPCR and AFC seven point Likert scale (1 = strongly disagree to 7 = strongly agree) instruments in the caregiver area of ‘perceived relationship with family’. The SPCR subscales *dominion* and *exclusion* measured staff perceptions of family and staff caregiving roles as sources of stress with many of the items analogous to the FPCR family instrument (subscale *conflict*). The AFC identified staff attitudes to family participation, based on critical incidences of responses from staff towards aspects of family involvement, with a higher score indicating a more

positive attitude (subscales *partnership*, *disruption* and *relevance* of family caregivers (see Table 6.2).

Perceived Relationship with Family

At Time 1 there were no significant site differences for the ‘perceived relationship with family’ subscale measures. At Time 2 independent *t*-tests identified significant site differences for the subscale *partnership* [$t(56) = -2.29, p < .05$], reflecting an improvement in staff attitude towards families at the control site and a slight deterioration at the intervention site (see Table 6.5). There was also an increased score for the subscale *exclusion*, reflecting an increase in stress at the intervention site with respect to staff attitude towards participation of family members in caregiving [$t(56) = -2.18, p < .05$], compared to the control site. The increase in staff stress at the intervention site for the subscale *exclusion* from staff towards families continued at Time 3 [$t(56) = -2.18, p < .05$], and Time 4 [$t(56) = -2.09, p < .05$].

Table 6.5 provides a summary of the mean scores at each site for the subscales *exclusion*, *dominion*, *partnership*, *disruption* and *relevance* from Time 1 to Time 4.

Table 6-5: Staff Attitudes Towards Families - Summary of Means Time 1 to Time 4

Measure	Control				Intervention			
	MT1 (SD)	MT2 (SD)	MT3 (SD)	MT4(SD)	MT1(SD)	MT2(SD)	MT3(SD)	MT4(SD)
Perceived relationship with family								
Exclusion	2.52(0.81)	2.41(0.90)	2.53(0.77)	2.52(0.74)	2.71(0.85)	2.98(0.89)	2.96(0.73)	2.92(0.73)
Dominion	3.33(0.83)	3.17(0.95)	3.25(1.18)	3.15(1.22)	3.54(0.87)	3.53(0.68)	3.43(0.67)	3.49(0.67)
Partnership	5.68(0.84)	5.80(0.86)	5.45(0.92)	5.56(0.94)	5.23(1.22)	5.21(1.06)	5.23(0.80)	5.33(0.88)
Disruption	5.12(1.05)	5.29(0.96)	5.38(0.97)	5.34(0.91)	5.16(1.05)	5.04(0.98)	5.09(1.01)	5.12(0.97)
Relevance	4.24(0.72)	4.30(0.99)	4.54(0.90)	4.51(0.85)	4.17(0.85)	4.27(0.90)	4.18(0.88)	4.15(0.91)

In summary, the hypothesis that staff attitudes toward families has improved at the intervention site compared to the control site for the subscale *partnership* is not supported. The hypothesis that staff stress has reduced with respect to working with families at the intervention site is also not supported. There were no significant changes at the control site. The following section presents the findings in relation to staff job satisfaction in relation to caregiving and organisational support.

Staff caregiver job satisfaction

Finally, Hypothesis 2 states that there will be an improvement in staff caregiver job satisfaction for those who participate in the FIC intervention compared to those who do not. Differences in job satisfaction were measured by the SPCR seven point Likert scale (1 = strongly disagree to 7 = strongly agree) instrument and the CSI seven point likert scale (1 = not stressful to 7 = very stressful) instrument in the caregiver areas ‘perceptions of caregiving’ and ‘perceptions of organizational support’ (see Table 6.2).

Staff Perceptions of Caregiving

When examining staff performance in relation to their ‘perceptions of caregiving’ various aspects of staff caregiver role and burden were assessed, as well as interactions and negotiations with family members within the subscales *task burden* and *role inadequacy*. Independent *t*-test analysis identified no site differences in ‘staff perceptions of caregiving’ for Time 1 through to Time 4. Paired samples analysis also detected no significant differences in the subscales *task burden* and *role inadequacy* from Time 1 to Time 4 at the control site or the intervention site.

The mean scores at each site for the subscales *resident harm*, *task burden*, *role inadequacy* and *resources* from Time 1 to Time 4 are summarised in Table 6.6 below.

Table 6-6: Staff Job Satisfaction - Summary of Means Time 1 to Time 4

Measure	Control				Intervention			
	MT1 (SD)	MT2 (SD)	MT3 (SD)	MT4(SD)	MT1(SD)	MT2(SD)	MT3(SD)	MT4(SD)
Perceptions of caregiving								
Resident harm	4.04(1.22)	4.00(1.35)	4.18(1.28)	4.08(1.26)	4.15(1.27)	4.36(1.15)	4.47(1.16)	4.41(1.34)
Task burden	2.43(0.97)	2.28(0.82)	2.40(0.87)	2.27(0.85)	2.54(0.94)	2.67(0.93)	2.54(0.94)	2.70(1.16)
Role inadequacy	4.40(0.98)	4.32(0.94)	4.29(1.11)	4.25(1.15)	4.67(0.79)	4.57(0.85)	4.67(0.71)	4.58(0.91)
Perceived Organisational support								
Resources	3.23(1.36)	2.90(1.37)	2.94(1.29)	2.11(1.26)	3.82(1.16)	3.98(1.11)	4.17(1.23)	4.12(1.36)

Further exploration of the subscale items for *task burden* and *role inadequacy* revealed specific responses from staff that suggested feelings of increased *task burden* and *role inadequacy* at the intervention site compared to the control site. This issue will be discussed in more detail in Chapter Eight. Paired samples analysis detected no significant within group changes from Time 1 to Time 4 in *task burden* or *role*

inadequacy at the control site or the intervention site. In summary, the hypothesis that staff job satisfaction has improved at the intervention site compared to the control site is not supported.

Perceptions of Organisational Support

The caregiver area ‘perceived organisational support’ (subscale *resource deficiency*) was measured by the CSI seven point Likert scale (1 = not stressful to 7 = very stressful) instrument (see Table 6.2). Staff caregiver stress is defined as the response that individual staff caregivers experience towards incidents that occur in the daily care of persons with dementia (Maas et al., 2000). No significant site differences were detected for the *resource deficiency* subscale at Time 1. However, at Time 2 the independent *t*-test identified significant differences between the two sites [$t(56) = -2.97, p < .05$], reflecting an increase in *resource deficiency* at the intervention site and a decrease at the control site. The differences continued at Time 3 [$t(56) = -3.71, p < .001$], and at Time 4 [$t(56) = -3.48, p < .001$], representing a further increase in stress, and decrease with job satisfaction at the intervention site.

The paired samples *t*-test also detected a reduction in stress at the control site with respect to *resource deficiency* from Time 1 to Time 3 [$t(26) = 2.11, p < .05$], and from Time 1 to Time 4 [$t(26) = 2.23, p < .05$]. The paired samples analysis detected no significant within group changes from Time 1 to Time 4 in ‘perceived organisational support’ (resources) at the intervention site. Table 6.7 summarises the between subject site differences for each of the staff caregiver subscales, and supports the discussion in Chapter Eight of each caregiver area through the identification of significant differences.

Table 6-7: Summary of Staff Member Between Subject Independent Samples t-test Baseline to Time 4

Measure	Time 1	Time 2	Time 3	Time 4
Emotional reaction to care recipient	t(56)	t(56)	t(56)	t(56)
Inappropriate Behaviour	0.26	0.70	-1.08	-1.17
Aggression	0.76	1.31	-1.35	-1.06
Perceived Relationship with family				
Dominion	0.78	1.61	-0.75	-1.34
Exclusion	0.64	-2.18*	-2.18*	-2.09*
Partnership	-1.52	-2.29*	1.01	0.98
Disruption	0.24	-1.10	1.10	0.88
Relevance	0.03	-0.25	1.55	1.56
Perceptions of caregiving				
Resident harm (safety)	0.26	0.92	-0.91	-0.94
Task burden	0.57	1.50	-0.57	-1.58
Role inadequacy	1.26	1.19	-1.52	-1.23
Perceptions of management				
Resources and support	1.60	-2.97**	-3.71**	-3.48**
Knowledge of dementia	-1.83	-0.92		

*p <.05 **p<.01

Table 6.8 on the following page presents a summary of staff caregiver within group findings.

Table 6-8: Summary of Staff Paired Samples t-test Baseline to Time 4 Across all Time Settings

Measure	Control							Intervention						
	Mean t ₁	Mean t ₂	t(26)	Mean t ₃	t(26)	Mean t ₄	t(26)	Mean t ₁	Mean t ₂	t(30)	Mean t ₃	t(30)	Mean t ₄	t(30)
Emotional reaction to care recipient														
Inappropriate Behaviour	3.00	2.90	0.58	3.10	-0.79	3.07	-0.50	3.07	3.18	-0.87	3.48	-2.10*	3.49	-2.09*
Aggression	3.80	3.58	1.06	3.79	-0.22	3.76	0.00	4.06	4.06	-0.49	4.29	-1.12	4.18	-0.51
Perceived Relationship with family														
Dominion	3.33	3.17	1.08	3.25	0.55	3.15	0.97	3.54	3.53	0.11	3.43	0.82	3.49	0.36
Exclusion	2.52	2.41	0.64	2.53	0.28	2.52	0.36	2.71	2.98	-1.77	2.96	-1.82	2.92	-1.31
Partnership	5.68	5.80	-1.27	5.45	0.97	5.56	0.50	5.23	5.21	0.09	5.23	0.03	5.33	-0.35
Disruption	5.12	5.29	-0.63	5.38	-1.27	5.34	-1.09	5.16	5.04	0.63	5.09	0.41	5.12	0.19
Relevance	4.24	4.30	-0.31	4.54	-1.91	4.51	-1.89	4.17	4.27	-0.86	4.18	-0.03	4.15	0.10
Perceptions of caregiving														
Resident harm (safety)	4.04	4.00	0.22	4.18	-0.65	4.08	-0.76	4.15	4.36	-1.28	4.47	-1.80	4.41	-1.24
Task burden	2.43	2.28	0.99	2.40	0.01	2.27	1.20	2.54	2.67	-1.19	2.54	0.00	2.70	-0.87
Role inadequacy	4.40	4.32	0.47	4.29	0.53	4.25	0.78	4.67	4.57	0.89	4.67	0.09	4.58	0.58
Perceptions of management														
Resources and support	3.23	2.90	1.38	2.94	2.11*	2.91	2.23*	3.82	3.98	-1.05	4.17	-1.71	4.12	-1.23
Knowledge of dementia														
	24.85	25.89	-2.05					26.10	26.45	-0.88				

* $p < .05$ ** $p < .01$

Summary of Staff Caregiver Quantitative Findings

The summary of the between subject analysis shows the differences in dementia *knowledge* between the sites at Time 1, representing a higher score at the intervention site. At both sites the *knowledge* test produced higher results at Time 2, with a lessening gap between the sites; however these differences were not statistically significant. In terms of staff caregiver stress, significant differences were identified between the sites at Time 3 and Time 4 for the subscale *exclusion*, reflecting greater stress at the intervention site. At the control site there was a significant decrease in staff stress associated with *resources and support* from Time 1 to Time 3 and Time 1 to Time 4. The analysis also reveals a significant difference at Time 2 in attitudes towards families (subscale *partnership*) at the intervention site. However these differences were not significant at Time 3 or Time 4.

Although not statistically significant, the staff caregiver results presented clearly show improvements in staff *knowledge* of dementia at the control site. The summary also reveals that there was a significant increase in staff caregiver stress in relation to ‘emotional reaction to the care recipient’ (subscale *inappropriate behaviour*) at Time 3 and Time 4. The next section presents a descriptive cross-cultural site comparison of staff measures, between both sites in this study, and comparisons to the Maas et al. study sites at Time 1 and Time 2.

Descriptive Site Comparison of Staff Measures: Australia and US

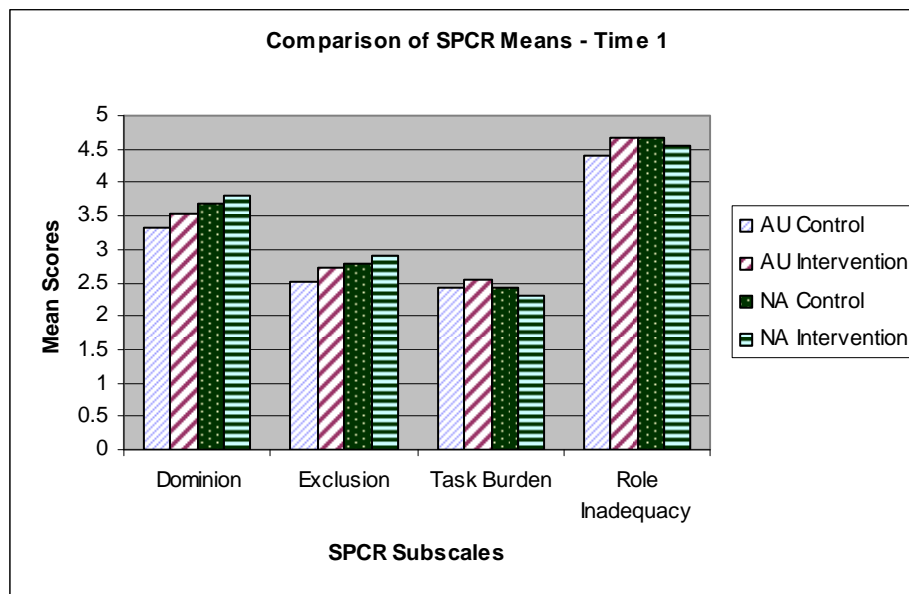
The aim of the descriptive site comparison is to establish any differences in the subscale outcome measures related to staff stress and satisfaction. Please note that Maas et al. study data were only available for Time 1 and Time 2. Each of the staff measures within the three staff instruments is presented in turn. Findings for the Staff Perceptions of their Caregiving Role (SPCR) instrument are presented in the next section.

SPCR Subscale Site Comparisons

The baseline (Time 1) stress level scores for the SPCR at the control site followed a very similar pattern to the Maas et al. study results, with the highest (worst) score for *role inadequacy* ($M = 4.40$), followed by *dominion* (resistance to sharing control of caregiving with family members) ($M = 3.33$), and *exclusion* (resistance to participation

of family members in caregiving) ($M = 2.52$). Mean scores were lowest (best) for *task burden* ($M = 2.43$). The trend was mirrored at the intervention site, with *role inadequacy* scoring highest ($M = 4.67$), followed by *dominion* ($M = 3.54$), *exclusion* ($M = 2.71$) and *task burden* ($M = 2.54$). All baseline scores were higher (worse) at the intervention site than at the control site, but the differences were not significant. The SPCR baseline cross-cultural and inter-site comparisons are summarised in Figure 6.1 below.

Figure 6-1: Comparison of SPCR Means at Time 1

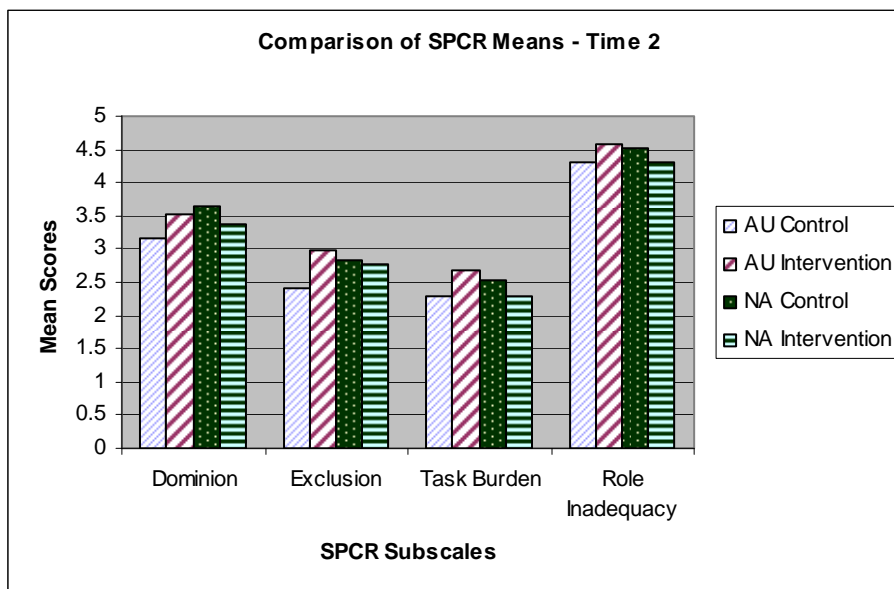


The SPCR Time 1 cross cultural comparison highlights the relatively low levels of staff stress at the Australian study control site, particularly in the subscales *dominion* and *exclusion*. These differences will be further discussed in Chapter Eight.

The post-intervention (Time 2) stress level scores on the SPCR followed a similar pattern to the baseline scores at both the control and intervention sites, with *role inadequacy* scoring highest ($M = 4.32$ and $M = 4.57$ respectively), followed by *dominion* ($M = 3.17$ and $M = 3.53$ respectively), *exclusion* ($M = 2.41$ and $M = 2.98$ respectively), then finally *task burden* ($M = 2.28$ and $M = 2.67$) respectively. It is worth noting that at Time 2 the mean scores for stress at the intervention site continue to remain higher than at the control site, with a significant difference detected between the two sites for the subscale *exclusion*, [$t(56) = 2.18, p < .05$] representing an increase in resistance for staff at the intervention site to participation of family members in

caregiving. Figure 6.2 below presents a summary of the SPCR cross-cultural and inter-site comparisons at Time 2.

Figure 6-2: Comparison of SPCR Means at Time 2



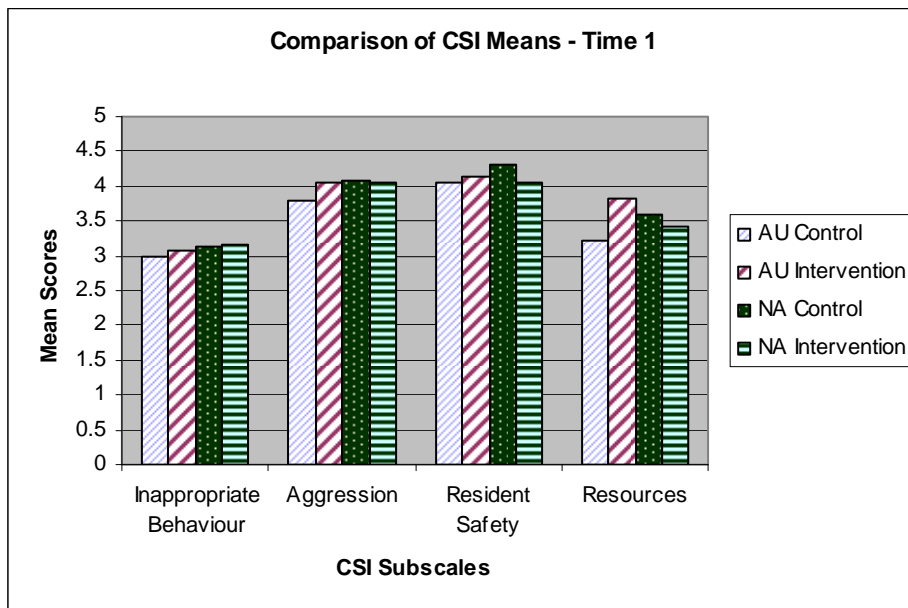
Once again the comparison at Time 2 highlights the lower staff caregiver stress levels at the Australian study control site. The following section presents a summary of the cross-cultural comparison at Time 1 and Time 2 for the Caregiver Stress Inventory (CSI), which measures the extent of stress experienced by staff caregivers associated with residents with dementia.

CSI Subscale Comparisons

The total mean CSI baseline (Time 1) score in this study for the control site was ($M = 3.52$) and for the intervention site ($M = 3.78$), compared to the Maas et al. study mean score of ($M = 3.60$), which was described by Maas (2001) as reflecting “moderate stress levels”. As with the total scores, the cross cultural comparison with the CSI subscales (*inappropriate behaviour, aggression, resident safety and resources*) also reveals a similar picture both within the sites in this study and the Maas et al. study scores. At the control site the highest score was for *resident safety* ($M = 4.04$), then descending to *aggression* ($M = 3.80$), *resources* ($M = 3.23$) and *inappropriate behaviour* ($M = 3.00$). The pattern was repeated at the intervention site, with the highest mean score for stress associated with *resident safety* ($M = 4.15$), then descending to *aggression* ($M = 4.06$), *resources* ($M = 3.82$) and *inappropriate behaviour* ($M = 3.07$). Again, the trend was for mean scores for staff stress to be higher at the intervention site than at the control site,

with no significant differences detected. Figure 6.3 below presents a summary of the baseline cross-cultural and inter-site comparisons.

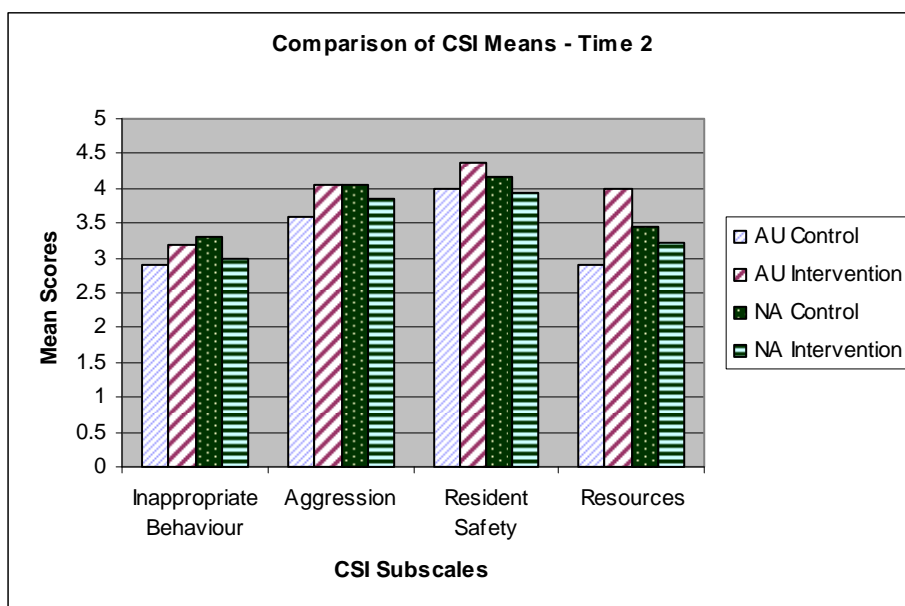
Figure 6-3: Comparison of CSI Means at Time 1



As with the SPCR at Time 1, the CSI cross-cultural comparison highlights the relatively low levels of staff stress at the Australian study control site, particularly in the subscale *resources*. These differences will be further discussed in Chapter Eight.

The total mean CSI Time 2 score in this study for the control site was ($M = 3.40$) and for the intervention site was ($M = 3.81$), representing a decrease at the control site and an increase at the intervention site. Overall the Maas et al. study score remained the same ($M = 3.65$). As presented in Figure 6.4, the major change at Time 2 at the intervention site was an increase in stress in relation to (lack of) *resources* ($M = 3.98$), whereas at the control site stress from *resources* reduced ($M = 2.90$). Staff stress in relation to *resident safety* also increased at the intervention site. Again, the trend was for mean scores to be higher at the intervention site than at the control site, with a significant difference identified between the sites for staff stress associated with the (lack of) *resources* subscale [$t(56) = 2.92, p < .05$]. A summary of the cross-cultural and inter-site CSI comparisons at Time 2 is presented in Figure 6.4.

Figure 6-4: Comparison of CSI Means at Time 2



The CSI comparison of means at Time 2 highlights the significant reduction in stress at the Maas et al. study intervention site for the subscale *inappropriate behaviour*.

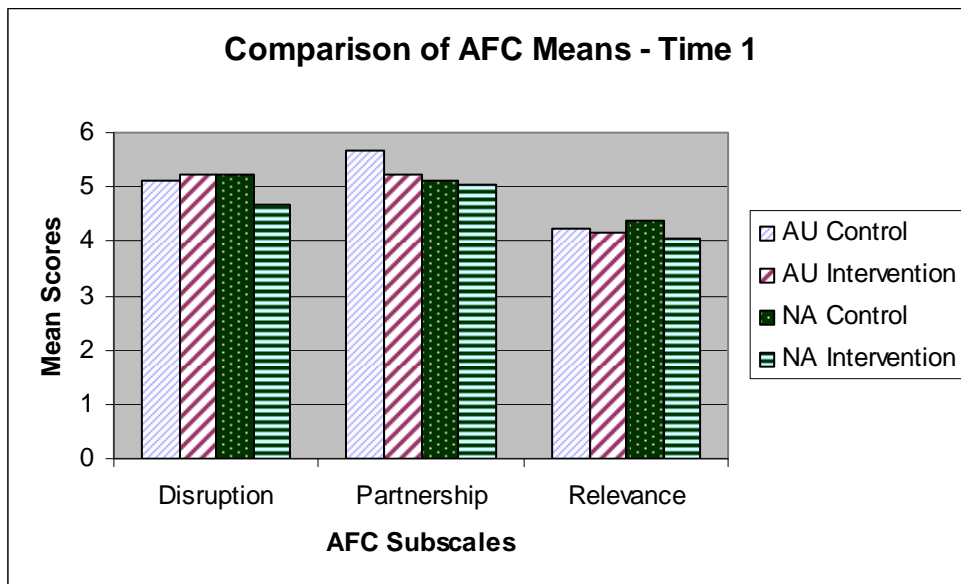
However, it is worth noting that staff caregiver stress levels at the Australian control site continue to be comparatively lower. The following section presents a summary of the cross-cultural comparison at Time 1 and Time 2 for the Attitude Towards Families Checklist (AFC), which measures staff attitudes towards families of residents with dementia, including family visitation, family requests regarding care of their relative, and family participation in the care of their relative.

AFC Subscale Comparisons

Total mean baseline scores for the AFC were ($M = 5.01$) at the control site and ($M = 4.85$) at the intervention site, with a possible range of 1 to 7. This result compares favourably with the Maas et al. study score ($M = 4.67$) for both sites in this study, with the control site outcome reflecting a favourable attitude towards families. Of the AFC subscales, scores were lowest (least favourable) for *relevance* (of family caregivers) at the control site ($M = 4.24$) followed by *calming* (lack of disruption by family caregivers) ($M = 5.12$) and *partnership* ($M = 5.68$). Similarly at the intervention site *relevance* scored lowest ($M = 4.17$), followed by *calming* ($M = 5.16$) and *partnership* ($M = 5.23$) highest. With the exception of the *calming* score, all results at the intervention site are lower than at the control site, giving an average total lower score for staff attitudes towards families. The individual subscales once again present a

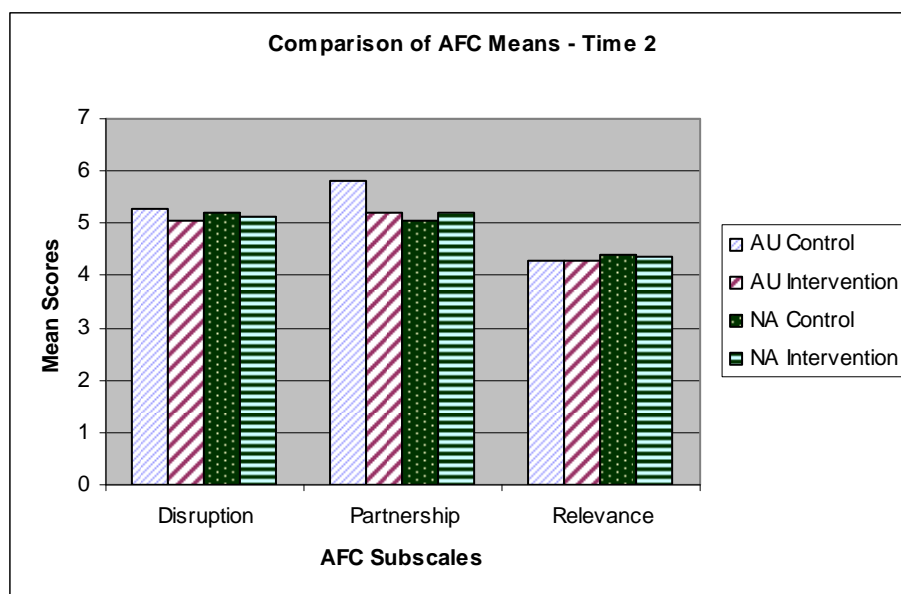
similar picture to the Maas et al. study subscale outcome results at Time 1 and are presented in Figure 6.5 below.

Figure 6-5: Comparison of AFC Means at Time 1



The Time 1 subscale comparison illuminates the higher score for *partnership* with respect to staff caregiver attitudes to families at the Australian study control site. At Time 2 the total mean baseline scores for the AFC were ($M = 5.13$) at the control site and ($M = 4.85$) at the intervention site, with a possible range of 1 to 7. This result for the control site compares favourably with the Maas et al. study score ($M = 4.92$) but attitude towards families is now lowest at the intervention site. At Time 2 the scores continue to be lowest for *relevance* at the control site and the intervention site ($M = 4.24$ and $M = 4.17$ respectively), followed by *calming* ($M = 5.12$ and $M = 5.16$ respectively) and *partnership* ($M = 5.68$ and $M = 5.23$ respectively). With the exception of the *calming* score, all results at the intervention site are lower than at the control site, giving an average total lower score for staff attitudes towards families. The individual subscales once again present a similar picture to the Maas et al. study subscale outcome results at Time 1 and are presented in Figure 6.6.

Figure 6-6: Comparison of AFC Means at Time 2



The higher score for the subscale *partnership* at the Australian study control site is evident again at Time 2, and will be further discussed in Chapter Eight.

Conclusion

The descriptive analyses of the staff caregiver stress measures reveal that at the Australian study intervention site, at Time 1 and Time 2, there were consistently higher stress levels compared to the control site, for the SPCR subscales *dominion*, *exclusion*, *task burden* and *role inadequacy*. Analyses of the CSI scores indicate moderate stress levels at both sites, with the mean score at the intervention site showing the highest score, compared to both the Australian study control site and the Maas et al. study sites. The scores from the AFC show that attitudes towards families at both sites compare very favourably to the Maas et al. study scores. However, the significant difference between the two Australian study sites at Time 2 represents an improvement in attitude towards families at the control site, rather than at the intervention site.

The between subjects and within subjects analyses reveal major changes at the intervention site at Time 3 and Time 4 in the caregiver area ‘emotional reaction to care recipient’, reflecting increasing stress with *inappropriate behaviour* of residents. Finally, the analyses highlight the significant differences in staff stress levels at Times 2, 3 and 4 in relation to *resource deficiency*, reflecting high stress levels at the intervention site for this subscale.

The following Chapter provides a discussion of the family caregiver post-intervention qualitative findings.

CHAPTER 7

FAMILY CAREGIVER POST-INTERVENTION QUALITATIVE FINDINGS

Introduction

This chapter presents an exploration of family caregivers' views on the success of the FIC education intervention. The aim of the post-intervention qualitative phase of the study was to provide an in-depth description of the experiences of family caregiver participants in order to clarify their views on the potential of the FIC care partnership. The findings from the interviews both support and clarify the effects of the intervention on family caregivers' perceptions of their involvement in the care of their relative with dementia.

Participant Sample

This purposive sample of family caregivers all participated in the pre and post-intervention interviews, with the exception of one male spouse whose partner with dementia passed away just prior to the post-intervention interviews. The interviews therefore involved five family caregivers from the intervention site and four from the control site. The breakdown for the intervention site was female spouse (1), daughters (3) and son (1). At the control site participants were female spouse (1), daughters (2) and son (1).

The aim of the interviews was to examine and compare family caregivers' views pre-intervention in relation to the fourth content area; 'evaluation of care in the facility' with their views post-intervention. The questions posed in the interview guide articulated with the four aspects of the FIC intervention protocol as follows:

- 1) **Increased family caregiver involvement in care** through orientation to the facility and the partnership role;
- 2) Education provided by the **Family Education Resource Manual**;
- 3) Negotiation of **the partnership agreement** (intervention site only); and

4) Improved ongoing **relationships with staff caregivers** who participated in the study.

The pre-intervention qualitative findings in Chapter Four revealed that within the content area ‘evaluation of care’ family caregivers emphasised the importance of a suitable therapeutic environment for their relative with provision of consistent staff presence, social interaction and opportunities for physical activities. During the pre-intervention interviews family caregivers expressed positive views about the physical care provided at both the control and the intervention sites. At the same time they also talked about their overwhelming and ongoing sense of loss as they perceived their relative with dementia slipped away from them. As the dementia progressed and the person with dementia became more unable to communicate his or her needs, families described how they sought more assistance from staff caregivers to fill the information gaps about how best to care for their relative. In turn, they sought to provide reciprocal personal information to staff about their relative, so that ‘the person’ with dementia could be cared for and understood by staff caregivers.

The pre-intervention interviews demonstrated that family caregivers sought to be involved in the care of their relative and were prepared to ‘fit in’ with staff in their caregiving role to ensure personal care needs, and thus well-being, of the person with dementia were met. The post-intervention interviews sought to clarify whether there was more family caregiver involvement following implementation of the FIC intervention protocol, with particular emphasis on answering the question: ‘Did the FIC intervention improve your caregiving role?’ The post-intervention interviews also explored the differences between family caregivers’ experiences of the placebo intervention at the control site, which did not include negotiation of partnerships and the formal ‘partnership’ at the intervention site. The interview guide is presented in Appendix C2. The qualitative interview findings are presented in the following sections.

Family Caregiver Involvement in Care

The responses at both sites to questions about family involvement were varied, reflecting the dynamic nature of how it may be perceived by individual caregivers. For example the two daughters at the control site, whose parent resided in the nursing home,

perceived no change in their involvement during the time of the study, stating that staff seemed to have “*less rapport*” with them than those they had engaged with when their relative was in the SCU. In comparison, the son whose mother was in the SCU at the control site felt that staff were more open to his input into her care since his participation in the study. The responses at the intervention site also were varied but generally more comprehensive, with such comments from a spouse whose husband was cared for in both the SCU and the nursing home as:

I found all the way through being involved in this program useful as it has given regular staff a better level of interaction, raised my awareness.

Interview #1, Janice

However there was also a sense from family caregiver responses at the intervention site that the level of involvement was affected by “*staff shortages there and the number of agency nurses*”. Indeed some family caregivers expressed the view that the staffing shortages caused by structural changes that had occurred during the course of the intervention had interfered with their involvement in care. One family caregiver confirmed her view by stating that “*I speak to other family members*” and the changes had impacted not just on her but on other family caregivers not involved in the study.

Nevertheless family caregivers believed that setting up the partnership did give them more involvement in care and that staff members generally responded well to their increased involvement. Family caregivers also identified the many barriers to continuing the partnership, ranging from either staff or their relative with dementia moving to a different section of the residential facility to staff resigning due to pregnancy. Family caregivers believed that these changes made it virtually impossible for some staff and families to achieve regular contact and update the partnership agreement when appropriate. At times it also became necessary for these family members to change their allocated staff caregiver, which interfered with continuity of care and completion of the activities identified in the Family-Staff Partnership Agreement. Furthermore, the general view from family caregivers was that their allocated staff caregiver only provided them with additional information about dementia care when they initiated the request.

In terms of the physical environment respondents at both sites expressed satisfaction with this aspect of care, with such comments as: *“I think mum is really happy here. I find her room bright and airy; I think she is reasonably happy”*.

Although the physical environment at both sites was described as satisfactory by family caregivers, at the intervention site one spouse’s comments about the provision of an environment conducive to the provision of activities for residents with dementia may serve to explain family caregivers’ lowered satisfaction scores in that area. She expressed her point of view about activities as:

It is important to be honest (about) activities. You can try to do this and do that but because dementia is as it is, it doesn’t often work. It is really important that they (families) know that, because otherwise they get very upset when they find out that it hasn’t happened.

Interview #4, Sally

This comment reinforces the view from families that providing physical care is only a part of the person-centred approach to addressing the needs of residents with dementia. These views are further clarified in the discussion about the Family Education Resource Manual

The Family Education Resource Manual

All respondents at both the control and the intervention sites found the Education Resource Manual useful. However they all believed that it could be further extended to assist families more. When asked how this may be achieved a number of valuable suggestions were made, as follows:

- Increase families’ knowledge about the dementia syndrome and its causes to reduce the stigma associated with dementia;
- Use in association with care groups and forums for families in residential care;
- Provide a copy to families when the person with dementia is first admitted to care;
- Provide the manual as part of the admission interview and orientation to the facility, combined with counselling about the impacts of dementia from trained staff, for example RNs, psychologists or social workers;

- Continue to build on new knowledge about dementia iteratively as new information comes to hand through newsletters produced by aged care service providers and forums;
- Ensure that a similar education tool is available for people at home to assist with some of the environmental issues associated with care of the person with dementia;
- Organise gatherings in the residential facility where family members could interact to share information, such as the resource manual;
- Provide further information on how to access other health professionals such as General Practitioners and Specialists through a website.

All family caregivers stated that they had read the education manual, with general comments made such as: *“it was very interesting, cemented some of my views”* and *“I now feel more acquainted with Alzheimer’s disease and dementia.”* One son described the difficulties he had encouraging his mother, who resided in the Low Care section at the intervention site with his father, who suffered from dementia, to read the manual. The son believed that his mother was still in denial about his father having dementia, and it was only towards the end of the intervention that she eventually read the manual.

The Family-Staff Partnership Agreement

In accordance with the FIC protocol, family and staff caregivers at the intervention site spent an additional agreed time negotiating the ‘partnership’ by completing the Family-Staff Partnership Agreement based on individual needs of their relative with dementia. The series of questions about the agreement, therefore, were asked to family caregivers at the intervention site only.

Family caregivers at the intervention site all found completion of the Partnership Agreement with their allocated staff member helpful. They described how individual activities identified in the agreement for their relative with dementia were satisfactorily completed. For example, *“having these audiotapes; dad has embraced it”* and *“we instigated the message book which I use now with the weekend staff”*.

However, with further probing about completing the agreement, two family caregivers described in more detail the difficulties in updating the activities with their allocated staff member. One respondent commented that *“my staff member left, I saw her once*

after the agreement.” Another respondent, whose husband initially was in the SCU, explained that although her allocated staff caregiver was in the SCU, *“the meetings weren’t worthwhile for me once my husband was moved to the nursing home”*. Despite these difficulties, overall the comments were generally constructive with one daughter commenting that *“the agreement was a good discipline for me; I focussed on getting the activities done.”* When the respondents were asked how many times they met or spoke with their allocated staff member they identified that they communicated with that person an average of nine times during the nine months duration of the partnership, either by telephone or face to face in the RCF. At this time, to avoid losing the agreements, it was decided by the researcher to keep them in a separate locked cupboard in the SCU Nurse’s Station. Consequently, although contacts were made between allocated family and staff caregivers, any changes to the activities were often not documented or updated on the Family-Staff Partnership Agreement due to the difficulties in coordinating access to the agreements from the other sections of the RCF.

Nevertheless the positive outcomes of the regular contact with staff were evident in the unanimous response from family caregivers that they had benefited, despite the environmental and staffing role changes identified. The accompanying reduction in stress was evident for some, reflected in such comments as *“learning more has reduced the stress”* and *“the study has provided me with a forum to let off a bit of steam”*. Family caregivers also believed that there had been some benefits for the person with dementia, particularly in relation to individual activities identified in the Family-Staff Partnership Agreement in the Low Care section of the facility. They believed there had been improvements for their relative during the time of the study, with such comments as *“she has improved out of sight”* and *“... staff are engaging with dad far more than in the past and he is more confident to talk about himself.”*

One daughter’s comments emphasised the difficulties in establishing and measuring the effects of the intervention on the person with dementia, as opposed to other changes in health and well being:

“That’s a difficult one to measure, yes probably, because I am a bit more aware so I go about things differently, but because dad’s mental state has improved so dramatically it’s hard to gauge whether he has benefitted from this or his own improved well being ... So much has happened that has benefitted dad physically and mentally and emotionally ...”

Interview #1, Janice

All respondents at the intervention site agreed that the partnership model of care has potential for success, making comments such as “*yes, it is essential and should be part of standard care*”, “*definitely should be in the SCU setting*” and “*should be supported by management*”. These comments provided a clear impression of family caregivers’ increasing understanding of the benefits associated with more involvement with staff when it is supported by a formalised agreement. Such comments as: “*All staff could do it, not just RNs and EENs*”, providing further support for staff who are intimate with their relative’s care. In comparison, at the control site there was a less informed and vague response by family caregivers, reflecting their lack of knowledge of the benefits of the formal agreement and ongoing contact with staff caregivers.

Family-Staff Partnership Activities

Table 7.1 below presents a summary of the activities chosen by family caregivers for inclusion in the Family-Staff Partnership Agreement. The activities most often identified in order of magnitude were grooming, individual exercise, assistance with eating, toileting, dressing, reminiscence and behaviour management.

Table 7-1: Activities Chosen by Family Caregivers in Family-Staff Partnership

GROUP	N = 29	Percent
Exercise	0	0.0%
Music	3	10.3%
Reminiscence	2	6.9%
Social Activities	6	20.7%
Other (TV, pastoral care)	2	6.9%
PHYSICAL ACTIVITIES		
Bath	8	27.5%
Toilet	6	20.7%
Groom	11	37.9%
Dress	6	20.7%
Eat	10	34.5%
Exercise	8	27.6%
Restraints (psychoactive medication)	5	17.2%
Other (hand massage, positioning, visual and audio impairment)	3	10.3%
PSYCHO-SOCIAL		
Reminiscence	6	20.7%
Behaviour Management	6	20.7%
Music	4	13.8%
Psychoactive medications	5	17.2%
Other (Audiotapes)	3	10.3%

The profile of activities chosen by family caregivers highlights their perception of the need for an increase in personal care, nutrition and individual psycho-social activities,

such as reminiscence and individual behaviour management. This gap in activities provided for residents with dementia was reflected in a number of comments made by family caregivers, particularly in the Low Care section of the facility, such as *“a few more activities for everybody ... desperate shortage of activities designed for the hostel residents that involve family ...”* This gap in the provision of personal care and individual psycho-social activities provided at the intervention site is reflected in the family caregiver quantitative findings.

Relationships with Staff Caregivers

Family caregivers expressed the development of their relationship with staff in a different context at the intervention site from the control site. At the control site family caregivers found it difficult to be forthcoming about any changes in their relationship with staff, making such comments, as *“even when they see you they don’t really give you any updates.”* In comparison, at the intervention site family caregivers were quite clear in their belief that their relationship with their allocated staff member had initially improved. However it became apparent that their initial increased expectation soon turned to frustration when the relationship was perceived to be blocked by environmental and role changes that occurred, for some as a result of their relative moving, for others the staff member moving from one section of the facility to the other. The resulting lack of contact meant that family caregivers ultimately lost the one on one interactive relationship with the staff member, resulting in decreased satisfaction with care. Nevertheless family caregivers’ support of staff was evident in such comments as *“the regular staff out there are very caring and provide a high standard of care”*.

Hence, responses about allocation to a staff member elicited different responses at the control site from the intervention site. Respondents at the control site did not feel they had benefited from the staff allocation and either did not see the staff member or *“did not have much do with her”*. In comparison, at the intervention site all respondents found the staff allocation useful, but made comments such as *“yes, but she didn’t stay; she changed positions and there was confusion”*, and *“yes, but she left the SCU – I didn’t see her a lot”*, and *“yes, but it didn’t last”*.

Although there were some comments about lack of communication with staff at the control site, at the intervention site it emerged as a major source of stress and dissatisfaction identified by family caregivers. They expressed ongoing dissatisfaction

with the lack of orientation and insufficient information provided, particularly by management and administration staff, either at the time of admission or when the resident with dementia was moved from one area of the facility to another. One family caregiver stated that *“they need to ensure administration staff are knowledgeable about dementia, especially at orientation”*. Family caregivers believed that as part of standard policy there should be formal recognition of the transition process and orientation should be mandatory. However, their reluctance to voice their concerns is reflected in one family caregiver’s statement that *“I could very easily have a huge amount of conflict with the admin(istration) staff, and for fear of it having any backlash on dad I’ve tended not to”*.

Family caregivers believed that this aspect of staff relationships was a source of major concern, reflected in such responses, as *“the biggest obstacle is lack of communication”* and *“that is all it comes down to, a shortage of staff members”*. Family caregivers talked also about the lack of commitment of temporary agency employed staff and their continuing disillusionment with the loss of regular staff, with such comments as *“continuity of staff is a must, but that is one thing I can’t see happening”*.

Spouses in particular found it very difficult when they felt they were ill-informed about what was happening to their loved one. The following statement highlights the importance of having a relationship with a staff member who is able to provide a balance of therapeutic interaction and informed honesty about the dementia syndrome. One spouse raised the fact that the ethical issues associated with providing information about the disease process itself and how it impacts on their relative should be part of the therapeutic interaction and relationship with a staff member:

The best thing to tell them right from the beginning is this is not going to get better, it is going to get worse and you need to accept that it is going to get worse. You can’t paint a pretty picture of it, it gets worse and it is going to end in death and you have to accept it.

Interview #2, Jenny

These comments reflect family caregivers’ views that a partnership with a regular staff member would encourage them to make informed choices about individualised care of their relative in residential care, based on acceptance of the deteriorating nature of the disease process. One daughter at the intervention site raised the issue of respect and honest communication from a different perspective. Her view originated from the perspective of facility management providing more support to family caregivers and

encouraging a sense of involvement with each other to enhance their relative's care.

She made the point that:

“ ... the sons and daughters are generally highly educated, highly schooled, successful people who collectively could have a voice ... if there was a forum to bring them together to stimulate that ... ”

Interview #5, Natalie

This observation is supported in the family caregiver demographic profile, which identifies the higher than average percentage of family caregivers at the intervention site with university education. However, all of the respondents at the intervention site commented on the lack of understanding or commitment from facility management in relation to encouraging family involvement generally, and in particular during the time of this study.

Conclusion

Family caregivers clearly identified that they would like greater involvement in care of their relative with dementia. They believe the FIC intervention has potential for success through the development of formal partnerships with staff if supported by facility management. Family caregivers found the education manual very useful and would like similar resources to be available and accessible earlier in the dementia trajectory.

Families found the Family-Staff Partnership Agreement to be very useful for identifying individual activities with staff members based on mutual knowledge and understanding of their relative's individual needs. However, the formal relationship with staff was not sustainable due to the occurrence of structural changes such as staff movement and resignation during the time of the study. Family caregivers identified several benefits for their relative with dementia, for example individual activities such as audiotapes available from the library and personal care, to increased communication on a personal and psycho-social level.

Family caregivers would like the Education Resource Manual extended so that it is included as part of standard care. They believe it would provide increased understanding of the benefits for families, staff and residents with dementia of partnerships in care. They expressed the view that communication with families as clients is “essential” to the well-being of the person with dementia, particularly during the later stages of decline. However the general consensus was clear that this approach

to care would not work without commitment from senior management and administration, and therefore, staff.

The following chapter presents an in-depth discussion of the findings in the context of the contemporary literature on family involvement and family-staff partnerships identified in Chapter Two.

CHAPTER 8

DISCUSSION

Introduction

This mixed method, sequential two-phase study was designed to test and evaluate the effectiveness of an education intervention and contractual arrangement between staff and family caregivers in residential dementia care. The study findings support the validity and reliability of the intervention as a means of improving family knowledge about dementia and increasing family involvement in care. However, the quantitative findings, together with the views of family caregivers pre and post-intervention, also provide evidence of the major barriers to the therapeutic “treatment effect” of the family/staff partnership, and thus its beneficial outcomes.

This chapter will examine the findings in relation to the literature discussed in Chapter Two about family and staff interventions in residential dementia care. The intervention and its components will also be compared with the previous findings in the Maas et al. study. There will be a critical discussion of the Quantitative Phase of the study in relation to answering the research hypotheses stated in Chapter Three, and the contribution this study makes to dementia research in Australia. The pre and post-intervention qualitative findings will be used to support the arguments advanced in relation to the intervention findings. Finally the study limitations and implications for future research will be explored to draw the major tenets for conclusions and recommendations.

A retrospective examination to detect inconsistencies with the Maas et al. study shows that this research has methodological strengths as a partial replication study. Firstly, this study utilised the pre-tested, standardised FIC instruments to test the replicable intervention in the Australian social, cultural and economic context of residential dementia care. Secondly, the instrument reliability measures for this study, as discussed in Chapter Three, compare well with the Maas et al. study, as does the extent of family involvement, or the “treatment effect” as presented in Chapter Five (see Table 5.2). Thirdly, the mean scores on the family and staff outcome measures follow very similar

trends, showing strong convergent validity with the Maas et al. outcome measures, with no major cultural differences detected either for family or staff caregivers (see Figures 5.1 to 5.4, and 6.1 to 6.4). Fourthly, as discussed in Chapters Five and Six, there was only one significant difference between the Australian study sites in any of the family and staff caregiver demographic categories, pre-intervention, for marital status. Finally, the comparison with the Maas et al. family and staff caregiver demographic information, which reveals a similar picture to this study, allows the results to be generalised, and the sample size used permitted statistical analysis with sufficient power. Furthermore, the pre- and post-intervention qualitative interviews enhanced the validity of family caregivers' perceptions and experiences about their involvement in care.

Family and Staff Caregiver Demographics

The two target populations in this study were family caregivers of residents with dementia living in residential care and staff caregivers working in residential care in Australia. Both the family and staff caregiver samples were drawn from two RCFs in Brisbane, Queensland. Using a control and an intervention group, and matching of the two facilities to control for pre-intervention differences between the two groups, reduced the risk of selection bias.

Family Caregiver Demographics

The first aim of the FIC intervention was to create a new role for family caregivers in the social system of residential care of residents with dementia (Maas et al., 2000). Demographic factors identified as having a potential influence on family caregiving roles were age, gender, ethnicity, education, occupation, marital status, ability to travel, type of relationship and same or younger generation relationship to the person with dementia. The comparison of family caregiver demographics in Table 5.1 identified no significant differences by intervention status for the two Australian sites. Similarly, with the Maas et al. sample in Table 5.1, there were no major differences for each of the characteristics. Nevertheless, it is worth noting that at both Australian sites, as well as in the Maas et al. study, the percentage of family caregivers with a minimum of tertiary study qualifications was very high at 30% when compared to the 2005 Australian national average of 23% (Australian Bureau of Statistics, 2005). This finding supports other studies that have found that people who are more highly educated are more likely to volunteer to participate in research (Haesler et al., 2006).

Family Caregiver Generation Comparison

When examining the factors or predictors that may have influenced the effects of the intervention on the role of family caregivers, there was a significant between generation difference identified in the Maas et al. results, where spouses felt more distress from the loss of their role as caregiver (Maas et al., 2004; Maas et al., 2000). Although in this study there were insufficient numbers to provide statistical analysis of generational differences, in the descriptive cross cultural comparison similar trends were identified (see Figure 5.5), particularly in relation to spouses' sense of loss. The resulting erosion of caregiver roles is discussed further in the sections 'The process and feelings associated with placement' and 'Changes in family and staff caregiver stress', and highlights the need for further research in these specific caregiver groups.

Staff Caregiver Demographics

Person-environment fit and role theory established that ongoing conflict with family caregivers deprives staff of the benefits of family support, personal information about residents, and adds to the stress of caregiving (Maas et al., 2004). Demographic factors identified as having a potential influence on staff caregiving roles were age, gender, number of years in occupation, education level, occupation level, employment status and marital status. The comparison of staff caregiver demographics identified the proportion of those who were married at the control site (n = 23, 85.2%) was significantly different when compared to the intervention site (n = 15, 48.4%).

A recent study by Sikorsda-Simmons (2005) examining levels of staff caregiver organisational commitment in long-term residential care has shown that there is a correlation between marital status and level of commitment to work. The major reason for the difference in commitment was identified as married staff's greater perception of responsibility both to family and financial needs (Sikorsda-Simmons, 2005). The higher number of unmarried staff at the intervention site may have been a contributing factor to the high level of staff turnover in that RCF. Another factor may be the impact of the rapidly expanding population in Brisbane, and Queensland, which generally may pose a significant influence on turnover, as opposed to attrition in the workplace. Because of the choice of positions and the ability for staff to find work easily, the increased mobility may be due to reasons of increased opportunity rather than a lack of job satisfaction (Eley et al., 2007). A number of other factors that contributed to the

changes to staff caregiving roles at the intervention site will be discussed further in the quantitative outcomes sections ‘Changes in family and staff caregiver stress’ and ‘Changes in family and staff caregiver satisfaction’.

The following section discusses family caregiver perceptions and experiences of their dementia caregiving role prior to implementation of the intervention. Reference is made to relevant research to confirm the findings of this qualitative phase of the study, and to highlight areas of additional knowledge.

Family Caregiver Perceptions of their Caregiving Role

The purpose of the first qualitative phase of the study was to explore family caregivers’ perceptions of their caregiving role as conceptualised by the person-environment fit and role theory frameworks (Woolcott, 2001). The theory proposes that the deterioration in physical and cognitive functioning as a result of dementia, combined with changes to the role of the family caregiver during placement from primary caregiver to outsider, results in stress (Maas et al., 2000). Thus the theory drives the question: ‘What does it mean to be a family caregiver of a relative with dementia who is placed in residential care?’

Caregiving Prior to Placement – Increasing Burden of Care

Family caregivers all talked about the increasing burden of care associated with caring for their relative with dementia at home. For spouses in particular the burden of care was exacerbated by denial, or at least uncertainty about a formal diagnosis, lack of knowledge about the condition and fear of the disease itself. The older generation’s sense of isolation was also increased by geographical distance from services and family. This, together with their inherent sense of stoicism, became a major deterrent for them actively seeking assistance from health professionals and family. Furthermore, for offspring, the symptoms of the early stages of dementia were often missed, either because of spousal compensation or because both their parents were in denial about the condition. Consequently the impacts of the increasing burden of care, combined with a lack of formal diagnosis, often went unnoticed, culminating in a crisis situation with varying degrees of physical and emotional impacts for both the person with dementia and family caregivers.

The study by Buhr (2006) explains these findings to some extent by providing evidence of the major factors associated with family caregivers seeking residential placement for the person with dementia as the need for skilled care, the caregivers' health and the need for more assistance. Buhr (2006) also emphasises the need for staff to validate with individual family caregivers the impact of caregiver burden, using them as clues to support discussion about residential care placement. This view is supported by Nolan and Dellasega (1999) who add that validation by staff of the decision to seek placement can be the beginning of promoting an environment that supports family involvement and their emotional reactions to care. Nevertheless it is clear from the experiences of this sample of caregivers that other factors specific to the Australian geographic and demographic landscape are also contributing to caregiver burden, such as travel distance causing isolation from services and lack of knowledge or understanding about the condition. These findings are supported in a literature review conducted by Brodaty et al. (2005), who concluded that Australian caregivers are reluctant to use available community services because of perceived lack of need, lack of knowledge and a level of stoicism which prevents them from applying for help.

Whilst the Australian Government continues to provide funding for on-line dementia specific services from government agencies, it may be questionable whether this target group has the knowledge and skills to access such support (Adelman & Daly, 2005; Robinson et al., 2009). One intervention study in the US has addressed the problems of isolation and lack of knowledge about access to resources by providing an immediate counselling program to those who have been diagnosed with dementia and the family caregiver (Whitlatch, Judge, Zarit, & Femia, 2006). In this country, Alzheimer's Australia provides education and counselling services to families whilst staff training is provided by specialist dementia education and training institutions, such as the Eastern Australia Dementia Training and Study Centre (EADTSC). However, it is increasingly clear that more promotion is required to increase the effectiveness of these family caregiver education programs within the community, and in the education of staff about the importance of family involvement in care.

Prior to residential placement some families attempted to relieve the burden of care through avenues such as respite care. However, their perception of an increase in negative behaviours from the person with dementia, both in respite care and when they returned home, often proved to be too stressful for caregivers. Neville and Byrne's

(2006) review of respite research supports this perception, claiming that instead of short periods in respite mitigating behavioural problems, they may actually serve to exacerbate them. The Australian Commonwealth Government has placed increasing emphasis on keeping people in their home and as a result has allocated increasing funds to carer services and respite care (Australian National Audit Commission, 2005). The increased family caregiver burden of heightened behavioural problems may help to explain the low uptake in some areas of in-home respite services (Queensland Health, 2006). This requires further investigation so that a more client driven approach to understanding of the needs of family caregivers for respite care can be identified and addressed.

It was clear that because of the long-term trajectory of dementia (average time requiring care at home for this sample was four years), the role changes for family caregivers prior to admission were subtle, and at times insidious, with varying degrees of detrimental physical and emotional burden for all family members. The prevailing message surfacing from the interviews supports the view of Maas (1991) that dementia is 'truly a family problem'. Furthermore, a number of studies support the pre-intervention interview findings that the continuing burden of care pressures for families did not cease at the residential facility door (Brodaty, 2007; Brodaty, Green et al., 2003; Cuijpers, 2005; Maas et al., 2004; Mills et al., 2004). Indeed, the transition to formal care created its own stressors, namely further experiences of the grief process and erosion of the family caregiving role.

The Process and Feelings Associated with Placement – Relentless grief

It was with some difficulty that family caregivers discussed the process of residential placement and the associated upheavals. The financial and administrative aspects of formal care overwhelmed most spouses, leaving this responsibility where possible to their children. Respondents expressed a sense of trauma associated with placement, and felt isolated from health professionals at this time. They expressed their frustration at the time of admission about the lack of support from, and communication with, staff trained and educated in dementia care. These aspects of caregiver burden are consistent with the US study conducted by Majerovitz (2007), in which stressors associated with burden are identified and used to guide residential care staff in providing more support for families.

When discussing their feelings associated with placement, family caregivers typically described overwhelming loss, sadness and guilt. Despite their own feelings, respondents were adamant about continuing their responsibilities as caregivers for the person with dementia in the spousal or filial role. This was particularly important for spouses, who not only faced the loss of their life-long partner, but also erosion of their role within the family structure. Such experiences described by families are consistent with earlier Australian and overseas studies that explore the impact on families of transitioning to residential care (Bauer & Nay, 2003; Gaugler, 2005a; Kellett, 1999, 2000; Maas & Delaney, 2004; Moyle et al., 2002; Woods et al., 2007).

An additional layer of experience identified in this study is the element of distress associated with the lack of meaningful involvement with health professionals prior to residential placement. This element of distress is borne out by the request from family caregivers for counselling. It also raises the question of whether an earlier response, prior to placement, is required from service providers, in particular from nurses who have a key role to play in assisting families to cope with the stressors of caring for their relative with dementia (Mason et al., 2003). This issue highlights the need for more education for all aged care nurses and other health professionals to increase their understanding of the complex process of the early assessment and diagnosis of dementia (Chong & Sahadevan, 2005; Robinson et al., 2009). Staff can then assist family caregivers in planning and making informed choices about their relative's care, as well as addressing their own needs for professional support and counselling.

The lack of meaningful involvement prior to placement may also explain family caregivers' wishes to increase their understanding and knowledge of dementia, the relentless grief associated with their relative's deterioration, and how best to care for them. The Maas et al. research identified that staff can help families overcome their grief through open communication, offers of education and opportunities to involve families in the care of their relative (Maas et al., 1994, 2004). This view is further supported in other work that examines the paradox of dementia caregiving for family caregivers, as they attempt to stay connected whilst having to let go of the person they knew (Bratt & Olenik, 2003). Staff can promote meaningful involvement for family caregivers by assisting them to negotiate new roles based on a common understanding of the person with dementia.

Relationships with staff – Seeking Connection and Meaning

Most family caregiver respondents felt that, particularly in the initial days of placement, they were isolated from the residential care staff with very little sense of involvement in their relative's care. Nevertheless, their sense of obligation to provide care drove their desire to develop a more communicative relationship with staff based on common understanding of their relative with dementia. The decades of work by Maas et al. on the benefits of building relationships with staff in the formal care environment supports the expressed need from this sample of family caregivers to remain involved in their relative's care. The work also supports the experience of these families that insufficient orientation to the facility during admission more likely results in family-staff conflict and ongoing dissatisfaction with care (Kelley et al., 1999; Kelley, Pringle Specht, & Maas, 2000; Maas, Buckwalter et al., 1994; Maas et al., 2004; Maas et al., 2001). Other studies also identify that improving staff-family relationships has the potential to reduce role conflict and improve the work environment, relieve the pressure of work overload, decrease staff frustration and reduce negative reactions to family involvement (Bauer, 2006; Davies & Nolan, 2006; Hertzberg et al., 2001). However, the quantitative findings from this study highlight that without sufficient ongoing support and leadership from management, staff experience of task burden and role inadequacy may actually be exacerbated as a result of increased family involvement.

Evaluation of Care – Looking After the Person

Family caregivers discussed evaluation of care within the specific areas of physical care, the environment, social/recreational activities and specialist dementia care. Overall, respondents seemed generally satisfied with the residential care environment, the level of physical care and the attitude of staff. Concerns arose, however, about the suitability of staffing ratios in the low care section at the intervention site, particularly for residents with dementia who were left alone for long periods of time. Similarly, concerns were raised with the physical layout of the high care section at the control site, emphasising the importance, as framed by person-environment fit theory, of the interplay between physical design, staffing ratios and the level of care provided to meet the needs of the person with dementia.

It is worth noting that the Maas et al. research focussed on the environmentally specific role of the SCU in improving family involvement in care of the person with dementia (Buckwalter et al., 1997; Maas, Buckwalter et al., 1994; Maas, Swanson et al., 1994; Mobily et al., 1992). Their research was based on the premise that in a constant environment continuity of care was more achievable, and resident, family and staff outcomes would influence each other dynamically (Kelley & Maas, 1999). In the current study, establishing those dynamics became more challenging and is reflected in family caregiver perceptions of lack of connection with staff, particularly outside the SCU environment. This finding is supported in other research which found that staff are more likely to have productive relationships with families in the specialised SCU environment, where residents' care needs are similar and care can be focussed accordingly (Pekkarinen et al., 2006). Furthermore, the secure environment of the SCU is more likely to reduce staff stress as fear of inappropriate behaviour such as resident wandering is reduced.

Recent work by Brush and Calkins (2008) also acknowledges the importance of environmental design in improving the care of people with dementia. In particular, large and inappropriately designed spaces can have a detrimental effect on the well-being of residents (Alzheimer's Australia, 2004). Respondents generally agreed that the SCU provided a more calming environment that was suitable for residents' social and physical needs. This inter-personal characteristic of SCUs has been identified in other studies, with associated benefits for both family and staff caregivers (Gaugler, 2005b; Gaugler & Ewen, 2005; Robinson & Pillemer, 2007). A recent evaluation of SCUs in the US by the Maas et al. researchers emphasises the positive effects of the environment on dementia resident behaviour and improved quality of life (Specht & Maas, 2008). The report also discusses the development of dementia specific assisted-living facilities for people with mild to moderate dementia. In comparison, Australia lags behind in both empirical research and development of a range of therapeutic environments that would be more suitable for people with dementia. This raises the need for further research that examines the role of the environment in catering for the needs of people with dementia and family caregivers.

There was a persistent and overriding experience of loss of control expressed by families in determining their role in the care of their relative. This sense was expressed on a number of levels, from the difficulty in seeing their family member in someone

else's clothes to the sense of loss of the 'person' they once knew as they continue to slip away from them. Associated with the family caregivers' sense of loss is the growing need for therapeutic communication with staff, driven by their concern that the needs of the 'person' will be met. However, insufficient trained nursing staff to provide such information and reassurance leads to increased stress for family caregivers, and consequent dissatisfaction with care. This finding highlights the impact of loss of trained RNs from the residential setting, and with them loss of the therapeutic relationship which is fundamental to their scope of practice. This has a particularly important impact on family caregivers as their relative with dementia suffers more profound decline and they adopt the surrogate client role (Stein-Parbury, 2009).

In summary, the major areas of concern highlighted by family caregivers in the Phase 1 qualitative interviews are lack of support from health professionals whilst still caring for their relative with dementia at home, and lack of meaningful relationships with staff following admission to residential care. Overseas, there is increasing evidence that effective family-staff relationships are integral to improving the well being of both family and staff caregivers and the person with dementia (Adams & Gardiner, 2005; Keady & Harris, 2009; Woods et al., 2008). Integral to achieving effective partnerships is developing a culture in aged care where staff members acknowledge the role expectations of family caregivers and assist them through the role and environmental transitions to accomplish the required care for their relative with dementia.

The following section presents the effects of the FIC intervention and continues to develop the "relation to context" with the Maas et al. research by linking the theoretical framework and replicated measurement tools specific to family and staff caregivers of persons with dementia within, and between, various residential settings (Buckwalter et al., 1997).

Effects of the FIC Intervention

The purpose of the quantitative phases of the study was to evaluate the outcomes of the FIC education intervention and contractual partnership in the Australian context. The outcome effects of the intervention are compared with the placebo intervention and the Maas et al. study outcome effects. Firstly, changes in family and staff caregiver knowledge will be discussed. Secondly, the changes in family and staff caregiver stress will be examined within the outcome clusters. Thirdly, family caregiver satisfaction and

staff caregiver job satisfaction will be discussed, with particular reference to staff attitudes towards families. A summary of the family and staff caregiver outcome clusters is presented in Table 3.1.

Changes in family and staff caregiver knowledge of dementia

The first hypothesis under investigation proposed that family and staff caregiver knowledge of dementia would improve following the education intervention. The post-intervention outcome effects for family caregiver knowledge of dementia were positive at both sites, with a statistically significant increase in knowledge at the intervention site. There was no significant difference between the sites for knowledge of dementia pre-intervention. The improvement in scores was evenly distributed across the three subscales identified in the FKDT instrument.

The improvement in family caregiver knowledge scores supports their views, as expressed in the pre-intervention interviews, that they require more knowledge of dementia and its impact on their relative. Their increase in knowledge also supports the views from family caregivers in the post-intervention interviews that the Education Resource Manual provided valuable information on dementia care. Furthermore, the significant improvement at the intervention site suggests a positive benefit of increased knowledge as a result of partaking in the formal partnership with a staff member. Such outcomes are confirmed by Bartlett et al. (2007), who provides evidence that an intervention is likely to be more successful if it aims, at least initially, to improve family caregiver knowledge and skills, rather than reducing the psychosocial effects of caregiver burden.

For staff caregivers, there were also positive improvements in knowledge. Prior to the intervention the level of knowledge was slightly higher at the intervention site than at the control site. Although not statistically significant, knowledge of dementia improved considerably at the control site, reducing the gap to achieve a similar result to the intervention site. It is worth noting that the majority of staff caregivers in the sample at both the control site and the intervention site were PCWs (51.8% and 67.7% respectively). The overall average post-intervention scores (26/33) indicate that staff caregivers in this sample did have a reasonably high general knowledge of dementia care. However, the scores would also suggest that for further improvement to occur ongoing specialised dementia education is required. A recent study examining

knowledge levels of nurse assistants conducted in Sweden by Furaker and Nilsson (2009) supports this view, claiming that their level of formal education is generally low, and their level of theoretical knowledge is generally lacking. The complex nature of dementia, its symptoms and impact on the person with the syndrome drive the need for suitably qualified staff with the skills to assess the needs of the resident in collaboration with family caregivers and other professionals, and to provide ongoing support and education for unlicensed staff. This professional approach to the provision of quality dementia care is clearly identified in Alzheimer's Australia's Practice Guide, in which the minimum requirement that PCWs receive ongoing education in dementia care is clearly stipulated (Alzheimer's Australia, 2007).

Changes in family and staff caregiver stress

The FIC intervention not only aims to address gaps in knowledge of family and staff caregivers, but also to improve their roles within the social construct of residential dementia care. Role theory predicates that family caregiver stress may be influenced by underlying feelings of loss, guilt and captivity, and these feelings may hinder their ability to participate in or control aspects of their relative's care. Similarly, staff caregiver's stress levels may be influenced by their sense of role inadequacy, thus hindering their ability to support family involvement in care of their relative. The FIC contractual partnership between family and staff caregivers aims to alleviate these stressors by negotiating changing roles and improving care for the person with dementia. The following sections examine whether the intervention was successful in alleviating these stressors associated with dementia care. Outcome effects will be examined for both family and staff caregivers, in the short-term (Time 2) and the long-term (Time 3 and Time 4).

The second hypothesis under investigation was that family and staff caregiver stress would reduce following the intervention. Stress outcome measures for both family and staff caregivers were categorised into the caregiver areas of 'emotional reaction to the care recipient' and 'perceived relationship with staff/families' (see Tables 5.3 and 6.2). Measures were analysed to identify any significant differences between the sites, and at each site longitudinally following the intervention.

Emotional Reaction to the Care Recipient – Family and Staff Caregivers

There were no significant differences between the control site and the intervention site for family caregivers with respect to ‘emotional reaction to the care recipient’ (subscales *guilt, captivity, loss*) at Time 1. There were also no significant changes in the subscales at either site from Time 1 to Time 4. It is interesting to note from the cross-cultural comparison that although the improvement in the sense of loss was significant in the Maas et al. study at Time 2, it was still comparatively higher than in this study (see Figure 5.2). Specifically, the Maas et al. results showed a statistically significant improvement in the subscale loss following the intervention for spousal (same generation) caregivers (Maas et al., 2000). Mittelman (2008) highlights that in psychosocial research an intervention may be effective with one category of caregiver and not another, depending on the cultural background and relationship of the caregiver to the dementia resident. Another major factor is the level of distress experienced by the family caregiver before placement, which may have long lasting effects on their stress and satisfaction levels (Gaugler et al., 2000). These factors alone may well explain the variability in stress between the sites in this study and in comparison to the Maas et al. study.

For staff caregivers there were no significant differences between the sites for the ‘emotional reaction to the care recipient’ (CSI subscales *inappropriate behaviour* and *aggression*) at Time 1, 2, 3 or 4. However, at the intervention site there was a significant increase in stress as indicated by the subscale *inappropriate behaviour*, at Time 3. Significant differences in stress levels between the control site and the intervention site were also detected at Time 2, 3 and 4 for specific item responses in relation to both residents’ *inappropriate behaviour* and *aggression*. The most notable cause of increased stress at the intervention site identified in the item responses was the increased time and attention required by residents from staff (see Table 6.4).

These findings are supported by a cross-cultural comparison (see Figures 6.3 and 6.4) using the CSI, in which it can be seen that, at the intervention site, staff stress in relation to residents’ *inappropriate behaviour* had already begun to increase at Time 2, whereas staff stress in the Maas et al. study had begun to decrease. Recent studies provide evidence of the relationship between *inappropriate behaviour* of dementia residents and staff stress (Lichtenberg, Kemp-Havican, MacNeill, & Schafer Johnson, 2005; Pekkarinen et al., 2006). Further research attempts to make sense of this relationship by

comparing staff stress levels in SCUs to those in non dementia specific areas of RCFs (Pekkarinen et al., 2006). There is increasing evidence to suggest that work stressors are reduced for staff in SCUs, compared to other sections of residential care, as staff are more likely to be trained specifically to care for the needs of residents with dementia. Consequently their experience of inappropriate behaviour is less stressful and therefore avoids role conflict (Pekkarin et al., 2006). This was the case for the Maas et al. study, whose sample was drawn from such dementia specific facilities.

A further premise in the Maas et al. research is that the psychological detachment that occurs as a result of staff burn-out limits staff ability to engage with residents and, without the skills and education required to overcome this problem, they find it increasingly difficult to cope with the behavioural problems of the person with dementia (Maas, Buckwalter et al., 1994; Mobily et al., 1992). Some of these US studies have found that the culture of support and innovation that mediate the effects of burn-out is more likely to be found in the SCU than in the RCF generally (Maas, Swanson et al., 1994; Mobily et al., 1992). Study findings also show that specialist staff training in dementia care is a critical factor in allowing staff to cope with the stressors inherent in their daily work (Mobily et al., 1992). As discussed previously it is difficult to draw such conclusions in this study because of the differences between SCU's in the US and those in Australia, and the latency periods between the studies. What is known is that at the intervention site, staff stress increased significantly in relation to residents' inappropriate behaviour at Time 3 and Time 4. The role stress and role strain felt by staff at the intervention site had a direct impact on family caregivers, resulting in conflict stress. It may also be assumed that because of the dynamic relationship between staff, families and residents, the stress felt by caregivers would be felt by residents, thus compounding their inappropriate behaviour. These findings emphasise the importance of relevant dementia training and support for staff from supervisors, so that they can therapeutically engage with families and the person with dementia, thus reducing their own as well as family caregivers' role conflict.

Family Perceptions of their Relationship with Staff (Stress from Conflict)

In this study it is person-environment and role theory that make the link between family-staff relationships, measures of stress and conflict in roles. The theory also forms the 'relation to context' basis between the contractual partnership and the 'treatment effect' of the intervention, which is based on role negotiation and family

involvement. This measure of family-staff conflict is an important indicator of the intervention's success in improving the well-being of both family and staff caregivers.

Although there were no significant differences between the two sites pre-intervention for the measure of *conflict*, by Time 3 family caregivers at the intervention site were exhibiting significantly more conflict stress than at the control site. This observation is supported by the cross-cultural FPCR site comparison of means at Time 1 and Time 2 (Figures 5.1 and 5.2), which also reveals a higher level of *conflict* at the intervention site compared to the Maas et al. study. Exploration of the individual item responses for the subscale *conflict* at Time 3 and Time 4 pinpoints the perception from families at the intervention site that their increased stress was associated with negotiating and resolving disagreements over the care of their relative (see Appendix G1). It is reasonable to conclude therefore that the additional stress for family caregivers may be due to the increased burden of participation in the contractual partnership at the intervention site.

This finding is supported by Maas et al. (2000), who argue that an additional source of stress for family caregivers may be the burden of participation in the study, particularly in relation to the time taken to complete the instruments at each time period. Another reason, as identified by Levy-Storms and Miller-Martinez (2005), may be that despite the perceived benefits of the intervention, the roles of family caregivers continue to be ambiguous, resulting in conflict with staff when not more clearly defined (Levy-Storms & Miller-Martinez, 2005). In this study, although the qualitative interviews with families identified some reduction in stress levels post-intervention, the quantitative findings suggest that role conflict was still an issue due to a lack of role definition when negotiating with staff, whose attitude to family caregivers was one of increasing, rather than decreasing, resistance to involvement in care. The reasons, as discussed in the following sections, primarily relate to increased *role conflict* and *task burden* for staff as a result of *resource deficiency*, which then directly impacted on the effectiveness of the intervention in alleviating their own and family caregiver burden.

These findings are consistently supported by evidence from pooled analysis of treatments that evaluate objective family caregiver burden that have identified no significant treatment effect in relation to reduced stress (Acton & Kang, 2001). In his earlier work Powell Lawton (1989) argued that there is a consistent pattern in the intervention literature where, for a number of reasons, quantitative analysis may not

detect a positive intervention effect but subjective evaluation by participants will show a more positive rating. In this study this is certainly the case when examining the views of family caregivers as identified in the post-intervention qualitative interviews. Clearly, the positive benefits for family caregivers of increased 'time to talk' during the interviews, whilst modest, did provide some short-term relief and reflect their understanding of how their involvement in care might also improve care for their relative. Some of the literature studies support the conclusion from this study that quantitative measurement alone is insufficient to identify the complexities associated with reducing stress associated with caregiver burden, and how improvements in family caregiving roles with staff might occur for the benefit of all (Acton & Kang, 2001; Powell Lawton & Rubinstein, 2000).

Staff Perceptions of their Relationship with Families (Stress from Exclusion)

A similar picture of increasing stress unfolds for staff caregiver's perceptions of their relationship with families, with significant differences emerging between the two sites from Time 2 to Time 4, reflecting an increase in stress at the intervention site with respect to exclusion of family caregivers. Further exploration of the items for the subscale *exclusion* clarifies how relationships with families have different characteristics at the control site from the intervention site. Staff perceptions of their relationship with families at the control site are reflected in the statements 'Working with families is an important part of my work', and 'I have mostly positive interactions with families'. On the other hand, the increase in staff stress at Times 2, 3 and 4 at the intervention site pertaining to the statement 'When family and staff have different ideas about care the disagreements are negotiated and resolved', suggests an increased resistance from them to involve families.

With reference to the theoretical framework, this finding would suggest that staff are experiencing increased role stress and task burden as a result of their inability to fulfil the expectation of the FIC partnership role (Pringle Specht et al., 2005). This increased resistance from staff to involving family caregivers directly impacts on the opportunity for either the staff or family participants to evolve their relationship within the formal partnership framework. For staff, the associated conflict with families deprives them of the benefits of family support and cooperation, personal information about residents and improvements to care for the person with dementia. Overseas researchers in the area of dementia care continue to emphasise the importance of mobilising family resources as a

means of evolving to a higher level of functioning and thus, standard of care (Keady & Harris, 2009). The findings in this study emphasise the importance of engaging appropriately skilled nursing resources to achieve those required care standards and effective family-staff partnerships.

The differences in staff resistance to family involvement between the sites in this study are supported by the cross-cultural site comparison of SPCR means at Time 1 and Time 2 (see Figures 6.1 and 6.2), which identify that staff stress from exclusion of family caregivers was already considerably lower at the control site when compared to the intervention site and the Maas et al. study. The Time 2 comparison also reveals the significant increase in staff stress at the intervention site to above the levels identified in the Maas et al. study. Reference to the theoretical framework would suggest that if staff are already experiencing role conflict as a result of task burden and role inadequacy, then involving families in a more formal relationship, as defined by the intervention, might serve to exacerbate the lack of benefits experienced by staff in their caregiving role, with an associated increase in stress (Pringle Specht et al., 2005).

The survey conducted in Australia by Brodaty et al. (2003), which examined factors associated with staff stress when caring for dementia residents, helps to make sense of these findings. Brodaty et al. (2003) concluded that individual site differences were more likely due to factors such as leadership styles, resulting in differences in a 'culture of acceptance' by staff caring for the dementia resident, rather than any family influences. The major research focus in Australia continues to be on examining the impacts of dementia resident behaviour on staff stress, rather than impacts from increasing family involvement. This current study provides additional evidence that without sufficient organisational support, the influence of family involvement may actually detrimentally impact on staff stress. In his study, Bauer (2006) contends that in residential dementia care in Australia there is still only a notional acceptance of families, and there is continuing evidence of the gap between the rhetoric of involving families and the attitudes and practices of staff in residential care. These findings support the view in Maas et al.'s research that if the intervention is sufficiently supported by the culture of the individual RCF, staff will benefit from increased family involvement. It may be argued that there were factors inherent in the leadership style, culture and the environment at the intervention site that actually created barriers to improvement in both staff and family caregiver stress (Mary & Melanie, 2006).

An important finding of the earlier Maas et al. studies was that role conflict between staff and families can have a detrimental effect on the quality of care provided to the person with dementia (Maas et al., 1991; Maas, Swanson et al., 1994; Mobily et al., 1992). What was also firmly established in the Maas et al. research was the dynamic nature of the relationship between staff, families and the resident with dementia. More recent research supports this view, and extends the importance of inter-relationships to include those between staff members and their supervisors as a means of reducing stress and improving job satisfaction (Robinson et al., 2007). However, in Australia it may be argued that these aspects of leadership and staff development will not be addressed without a shift in culture at the organisational level, and acknowledgement at the policy level, of the need for increased professional resource requirements in aged care, particularly RNs.

Changes in family and staff caregiver satisfaction

The second hypothesis under investigation also proposed that family satisfaction with care and staff caregiver job satisfaction would improve following the intervention. Within the person-environment fit and role theory framework, satisfaction measures reflect congruence with care and dissatisfaction is defined as the “manifestation of stress in response to the discrepancies between reality and expectations” (Maas et al., 1994, p. 23). Family satisfaction was measured in the areas of dementia caregiving related to *physical care, activities, staff consideration* and *management effectiveness*. Staff job satisfaction measures related specifically to the area of perceived organisational support.

Family Perceptions of Relationships with Staff (Satisfaction with Staff Consideration)

At the intervention site the family caregiver satisfaction findings for the subscale measure ‘perceptions of staff *consideration* towards families’ presented a similar picture from Time 1 to Time 4 to the stress subscale *conflict* for ‘perceived relationship with staff’. Once again there were no significant differences detected between the sites at Time 1. However, by Time 3 the findings show that family caregivers were significantly less satisfied with staff consideration at the intervention site than at the control site. Further exploration of what may have occurred revealed an improvement in satisfaction at the control site compared to the intervention site for the response item ‘staff provide support to help me deal with my feelings about my family member’s situation’, resulting in significant differences in family caregiver satisfaction (see

Appendix G1). It is worth noting that the increased satisfaction at the control site may reflect positive improvement from more 'time to talk' for family caregivers as a result of the placebo intervention.

From a cross-cultural perspective the inter-site means comparison for Time 1 and Time 2 indicated a higher level of satisfaction at the control site compared not only to the intervention site but also to the Maas et al. study (see Figures 5.3 and 5.4). Indeed, the significant improvement in family satisfaction with staff consideration at Time 2 presented in the Maas et al. findings sees it just below the level of this study control site. Moreover, at Time 1 the Maas et al. satisfaction level is below the mean satisfaction score for this study intervention site, suggesting that pre-intervention family satisfaction with staff consideration was reasonably high at both Australian sites prior to the intervention. Nevertheless the decreasing satisfaction at Time 3 and Time 4 at the intervention site requires further investigation.

The longitudinal study by Levy-Storms and Miller-Martinez (2005) indicates that family caregivers who are more involved in their relative's care are actually less satisfied with staff, particularly when there are staff shortages. This finding is supported in Tornatore and Grant's (2004) cross-sectional survey, which identified that if a family caregiver's experience is consistent with their expectations and they maintain trust in the service provider, they are more likely to be satisfied. Furthermore, families are more likely to remain involved in the care of their relative if actually encouraged to do so by residential care staff (Reid et al., 2007). Comments made by families in the post-intervention qualitative interviews highlight the importance to them of a relationship with staff based on mutual role definition, trust and satisfaction. For families at the intervention site it was not possible for this relationship to be sustained. This finding raises major implications for aged care service providers to disseminate promotional information about their services which is not only relevant to clients but is also deliverable to meet their needs.

The longitudinal findings from this study also suggest the presence of other confounding influences which may explain the significant decrease in family satisfaction with staff consideration over time at the intervention site. During the nine month period of the study, the impact of workplace structural changes resulted in staff movement within different sections of the intervention site and loss of trained RNs. It

also resulted in the exposure of family caregivers to temporary ‘agency’ staff, whose personal knowledge of their relative would be limited. These changes may well have impacted on family caregiver perceptions of staff consideration, and their responses to the self-reporting questionnaires. In their guide to quality dementia care standards, Alzheimer’s Australia identify stable staffing patterns as a minimum requirement of management to meet the needs of dementia residents and their families (Alzheimer’s Australia, 2007). These findings suggest that in some environments in residential dementia care these minimum requirements are not being met.

Family Perceptions of Care and Management Effectiveness (Satisfaction)

At the control and intervention sites, family satisfaction with *physical care* remained constant both prior to and following the intervention, with the exception of some site differences at Time 2. This constant level of satisfaction with *physical care* is reflected in the family caregiver comments made in the qualitative interviews in Phase 1 and Phase 2 of the study. Maas et al. (2000) argue that, particularly in relation to *physical care*, family expressions of satisfaction may be more an acceptance of the lack of care options available than genuine satisfaction with the quality of care their relative is receiving. In contrast to this study, in the Maas et al. study family caregivers were statistically significantly more satisfied with *physical care* post-intervention.

The cross-cultural comparison shows that the significant improvement in the Maas et al. study resulted in family caregivers having the same level of satisfaction as that already observed in both Australian sites prior to the intervention (see Figures 5.3 and 5.4). This would suggest that, despite staffing shortages, staff are maintaining a satisfactory standard of *physical care*. Nevertheless it is important to note that the data collected from the Maas et al. study is from a decade prior to this study, during which there have been a number of changes to regulatory reform resulting in improved standards of care. It may be argued that when examined retrospectively, the Australian 1997 Aged Care Act Reforms have positively influenced the development of higher standard residential facilities for the provision of quality care. Providing sufficient levels of nursing staff with the appropriate skills to effectively lead in aged care becomes the next challenge for service providers and policy makers (Angus & Nay, 2003; Hogan, 2004).

For the subscale (psychosocial) *activities*, families were consistently more satisfied at the control site, with a significant difference between the sites detected pre-intervention

particularly in relation to activities related to sensory stimulation. There was a slight improvement in satisfaction at Time 2, but as indicated in the cross-cultural comparison (Figures 5.3 and 5.4), the satisfaction levels at the intervention site are well below those observed at the control site and the Maas et al. study sites. Further examination of the mean item responses for the subscale *activities* show significant differences between the control and intervention sites in satisfaction with the amount of *activities* provided and the staff resources available to provide care, particularly for residents to enjoy outdoor and other diversions (see Appendix G1).

These reduced satisfaction outcomes are consistent with the changes observed at the intervention site during the course of the study. It is worth noting that one (out of two) Diversional Therapist who played a significant role in providing activities at the intervention site did not participate in the study. Her lack of commitment to family involvement alone may have had a major effect on family satisfaction with respect to psychosocial *activities*. Research supports this observation by emphasising that an important aspect of family involvement in care is ensuring their relative is involved in psychosocial *activities* (Gaugler, 2005a; Kellett, 2007; Toranatore & Grant, 2004). For this to be achieved commitment from management and core dementia specialist staff such as Diversional Therapists is essential.

Although there were no significant differences detected at Time 1, family satisfaction with *management effectiveness* decreased significantly at both sites during the time of the study, but more so at the intervention site at Time 2, Time 3 and at Time 4. A significant decrease was also detected at the control site at Time 3. Further exploration of mean item responses once again highlights the lack of staff resources as the major source of increasing dissatisfaction at the intervention site (see Appendix G1). This observation is supported and clarified by family caregiver comments in the post-intervention interviews.

Examination of the cross-cultural means comparison for Time 1 and Time 2 (Figures 5.3 and 5.4) clearly highlights higher family satisfaction with *management effectiveness* at the control site at Time 2 immediately following the intervention. However, analysis of the observations at Time 3 and Time 4 reveal that family caregiver satisfaction with *management effectiveness* was not sustainable at either site. Once again, the

comparison at Time 1 and Time 2 with the Maas et al. mean scores reveals a higher level of satisfaction with *management effectiveness* at the Australian control site.

In their study findings, Maas et al. (2000) identified the major barrier to family satisfaction with *management effectiveness* as the lack of leadership by RNs and lack of commitment by management to promote the family-staff partnership intervention. Subsequent FIC studies have focussed on the need for health professionals and managers to understand more about family perceptions of care, so that individual adjustments in residential care can occur with as little distress as possible (Maas et al., 2004; Maas et al., 2001; Pringle Specht et al., 2005). Similarly, researchers in the UK led by Nolan (2004) support the imperative that partnerships between families and staff are a potential resource for improving the resident quality of care. This study further supports the call for industry to support research that builds knowledge and understanding of how productive family-staff partnerships can enhance care through client driven, rather than organisation driven, approaches. Such a framework would progress person-centred approaches within the three person triad of dementia care.

Staff Perceptions of Relationships with Families (Attitudes)

The AFC measured staff attitudes towards family involvement from the perspectives of family visitation, family requests regarding care of their relative, and family participation in the care of their relative. The measurement tool assessed whether staff believed that family caregivers are disruptive, whether they are irrelevant to care, and whether they should be partners in care. No significant differences between the sites were detected at Time 1. The post-intervention findings provide evidence that for the subscale *partnership* there is a significant difference in staff attitudes at Time 2, representing an improvement at the control site and deterioration at the intervention site. These observations are supported by the cross-cultural comparison of AFC means at Time 1 and Time 2 (see Figures 6.5 and 6.6), which identify that staff perceptions of a partnership relationship with families was already high at the control site compared to both the intervention site and the Maas et al. study.

There is evidence from recent studies that an important salient influence on staff attitudes is their understanding of dementia and the notion of person-centred care (Brodaty, Green et al., 2003; Zimmerman et al., 2005). It may be argued from the positive findings associated with level of staff knowledge and attitude at the control site

that a culture of person-centred dementia care had already developed prior to this intervention. This culture was also evident to a lesser degree at the intervention site and is supported by the comments made by family caregivers prior to the intervention. However the findings suggest that at the intervention site, staff's perceived confidence in providing person-centred care was detrimentally affected by lack of support from management and structural changes within the RCF. Another important aspect of staff attitudes to families is the quality of their relationship with the person with dementia. Recent overseas caregiver research provides strong evidence that, as with family well-being, staff caregiver well-being also impacts on the well-being of residents (Gaugler, 2005a; Gaugler & Ewen, 2005; Zimmerman et al., 2005). This evidence emphasises the importance of a management culture and nurse leadership that supports staff in their caregiving role as a means of improving attitudes towards families and, therefore, quality of care for residents with dementia.

Staff Perceptions of Caregiving (Job Satisfaction)

When examining staff performance in relation to their 'perceptions of caregiving', various aspects of staff caregiver role and burden are assessed, as well as interactions and negotiations with family members. Further exploration of the subscale items *task burden* and *role inadequacy* revealed specific responses from staff that suggested feelings of increased *task burden* and *role inadequacy* at the intervention site compared to the control site (see Appendix G1). This difference is also revealed in the comparison of SPCR means at Time 1 and Time 2 (see Figures 6.1 and 6.2), which shows that at Time 2 in the Maas et al. study there was some improvement in stress due to lesser feelings of *role inadequacy*. However this was not the case at the Australian intervention site.

Studies examining the relationship between stress and satisfaction in nursing home staff emphasise the importance of training in dementia care to improve stress due to role inadequacy and thus job dissatisfaction (Brodaty, Draper, & Low, 2003; Zimmerman et al., 2005). Alzheimer's Australia's care standards support this relationship from a human resource perspective by stating that as a minimal requirement management should "Promote staff satisfaction by involving all personnel in decision making about care delivery" (Alzheimer's Australia, 2007; p10). Once again the need for nurse leadership in providing collaborative and decision making support to unlicensed staff about care delivery is emphasised.

Staff Perceptions of Organisational Support (Job Satisfaction)

In this instance staff caregiver stress is defined as the response that individual staff caregivers experience to incidents that occur in the daily care of persons with dementia (Maas et al., 2000). Role theory acknowledges the link between stress associated with resource deficiency and job satisfaction. The longitudinal observations in this study allowed a very clear picture to emerge of the differences in organisational support between the two sites. There were significant differences between the two sites at Time 2, Time 3 and at Time 4.

Further exploration of the subscale items for *resource deficiency* revealed differences between the sites for three out of the seven items of the *resource deficiency* subscale. The differences between the sites continued to increase, particularly in relation to the 'lack of resources (management commitment) to care appropriately for the residents', and the 'lack of a unified approach among all disciplines and administration to care for and assume responsibility for the residents' care' (see Appendix G1). The responses from staff at the intervention site reflect their increased level of stress from lack of perceived organizational support, resulting in decreased confidence in their abilities and knowledge with respect to caring for the person with dementia. This observation is also very clearly reflected in the CSI cross-cultural comparison (see Figures 6.3 and 6.4), where stress associated with resource deficiency at the Australian intervention site is the highest compared to the lowest at the control site.

There is increasing evidence that at an organisational level supervisory support has a major impact on staff stress and job satisfaction, resulting in increased attrition and turnover (McGilton & McGillis, 2007). Another impact on staff well-being is their satisfaction with the culture of the care organisation and the environment (Zimmerman et al., 2005). It is clear that a major contributing factor to the perception of lack of organisational support at both the control and the intervention sites was the disruption caused by structural changes related to staffing and management that occurred during the time of the study. What this raises is the importance of evaluating the success of an intervention over a sustainable period of time, rather than at one point, as a means of capturing cultural influences on the dynamics of family-staff partnerships in a complex environment.

In summary, the aim of the FIC instruments is to capture the multi-dimensional elements of stress caused by care burden perceived by families and staff, and the impacts on their levels of satisfaction (Pringle Specht et al., 2005). This discussion of the quantitative findings aims to draw together the similar dimensions of stress and satisfaction for staff and family, as framed by person environment and role theory, so that links between client driven care and the culture of the care environment can be formed.

The following section provides a discussion of the post-intervention qualitative interview findings.

Family Caregiver Evaluation of the Intervention

The purpose of the second qualitative phase of this study was to clarify family caregivers' views on the success of the FIC intervention in promoting greater family involvement in care, and to enhance interpretation of the quantitative outcomes (Mittelman, 2008). The interview framework focussed on the fourth pre-intervention content area identified in the first qualitative phase, 'evaluation of care'.

Family Caregiver Involvement in Care

All family caregivers at the intervention site confirmed that setting up the partnership agreement did provide them with more involvement in their relative's care. Although their responses were mostly positive, they also clearly identified many barriers to continuing the partnership, such as structural staffing changes and environmental changes for the person with dementia. There was a general sense from family caregivers that staff caregivers were unable to maintain the level of commitment necessary to continue the partnership, leaving them to initiate ongoing communication about the care of their relative with dementia. These findings are consistent with those of other studies that highlight the lack of encouragement from staff to involve families in care (Aveyard & Davies, 2005; Hertzberg et al., 2001). Such findings underline the need for more empirical research focussing on therapeutic staff-client relationships and on evaluating the effectiveness of interventions that take into account 'family as client' outcomes (McGarry Logue, 2003).

The Family Education Resource Manual

All family caregivers received a copy of the Education Resource Manual and found it very useful. There were a number of suggestions made to extend the manual further, with particular emphasis on providing access to the information earlier in the dementia trajectory, preferably at the time of diagnosis. All family caregivers believed their knowledge of dementia had improved. This issue of access to information was also highlighted in the pre-intervention family caregiver interviews as a major barrier to improving the transition to residential care. Not only is more accessible information needed for families about dementia care, but also about the availability of specialised services and support for families (Adams & Gardiner, 2005; Tilly & Rees, 2007; Toranatore & Grant, 2004). Nursing researchers in Australia are increasingly recognising that access to information and professional services is a fundamental need for family caregivers and the person with dementia (Robinson et al., 2009).

The Partnership Agreement

All family caregivers at the intervention site found completion of the partnership agreement helpful and described how the activities documented in the agreement were completed. Although each family member spoke with the allocated staff member an average of six times for each month of the intervention, therapeutic changes to the agreement were not included as part of standard care. Consequently, although family caregivers talked about some reduction in stress, they did not benefit from the full therapeutic treatment effect of the intervention. Zarit and Femia (2008) raise the issue that if therapeutic processes are not followed there will be insufficient treatment dosage to affect intervention outcomes. This was particularly the case in this study, even though family interviewees did identify some beneficial intervention effects, such as reduced stress and improved relationships with staff.

Some family members mentioned improvements in their relative's well-being as a direct consequence of their increased involvement. Accordingly they believe the partnership agreement has potential for success if promoted as part of standard care and supported by management. Family caregivers believed that with the right training, education and leadership, all staff could include family involvement in their scope of practice. Furthermore, there is a growing body of evidence that care partnerships have the potential to provide solutions to improving the roles of family caregivers, and thus

productive relationships in dementia care (Bauer, 2006; Levy-Storms & Miller-Martinez, 2005).

Relationship with Staff Caregivers

Family caregivers expressed the development of their relationship with staff in a different context at the intervention site from the control site. At the control site family caregivers found it difficult to be forthcoming about the relationship, as nothing formal was established. In comparison, at the intervention site there were initially improvements in relationships with staff, which flowed from individual negotiation of the agreement and discussion about care on a personalised basis. This soon turned to frustration and disappointment when continuity of care was usurped either by staff moving, resulting in changes to their caregiver roles, or their relative moving from one section of the facility to another. For family caregivers the changes ultimately meant inability to sustain the interactive therapeutic relationship, with resulting dissatisfaction with the care environment. Recent studies indicate that this lack of continuity is emerging as a common barrier to intervention research, particularly in dementia care (Mittelman, 2008; Zarit & Femia, 2008).

The disruption to sustaining family-staff relationships was also raised by family caregivers as the greatest obstacle to promoting and encouraging family involvement in dementia care. The continuing disillusionment for families with loss of regular staff was compounded by the lack of commitment from site management and administration in promoting the family involvement research. Spouses in particular raised some ethical issues associated with family and residents' rights, and with service providers making available essential information about care delivery. They believed that, specifically for dementia care, this should include individualised information about the disease process itself and how it impacts on their relative. Interviewees believed that honest information sharing should be part of the therapeutic interaction and relationship with all staff members, so that the best standard of care is provided for their relative with dementia. This approach would also provide more meaningful interchange about the individual needs of their relative and person-centred care.

Other studies provide evidence of the desire among family caregivers to remain involved, adjust to change, and participate in meaningful caregiving through effective communication (Kellett, 2000, 2006; Robinson et al., 2007). This includes monitoring

care, providing for the personal needs of their relative and ensuring their rights are upheld (Gaugler, 2005a; Ward-Griffin & McKeever, 2000). This issue of information sharing between staff and families about the needs of the person with dementia is also addressed in the Clinical Care section of the Alzheimer's Australia Quality Dementia Care Standards Guide (2007) and the ANMC Nursing Competencies (2006).

In summary, the post-intervention interviews provided a valuable insight into the success of the FIC intervention in the Australian context and how future research may improve its implementation. Family caregivers also provided confirmation of the limitations of study. These will be discussed in the following section.

Limitations of the Study

The study limitations are discussed within the areas of design, sample size, intensity of the treatment effect and intervention feasibility. Future research with respect to each area will be suggested.

Study Design

The longitudinal design presented problems in maintaining a consistent environment so that the data collection at each time period could be undertaken without contamination by external influences. Consequently, although the study sites were matched to reduce study bias, it was possible to identify other confounding environmental influences that affected the success of the intervention compared to the Maas et al. study. These confounding influences were mainly derived from the necessity to draw the study participants from all levels of care in the RCF (low care and high care) as opposed to dementia-specific care in the SCU. This meant that the sense of ownership of the partnership, both for families and staff, was impeded by other influences such as decreasing permanent staff numbers and changing staff roles in the non-dementia specific areas of the facilities, even though these residents were formally diagnosed with moderate to severe dementia. These influences also made it difficult for families and staff to maintain formal contact, thus impacting on the collection of information in relation to the minimum therapeutic dose or 'treatment effect' of the intervention.

Sampling

The small sample size was a known limitation. Nevertheless, the findings are important and are supported in the qualitative findings in relation to significant improvement in

dementia knowledge. Furthermore, the positive responses from family caregivers in the post-intervention interviews support the notion of improved involvement with a staff member. However, at the intervention site these responses were not reflected in significant reductions in stress post-intervention as a result of increased involvement. The comparison with the Maas et al. study results (sample size of 185 across control and intervention sites) suggests that the lack of significant findings in this study may also be related to the limited sample size of 57 family members (27 at the control site and 30 at the intervention site).

Intensity of the Treatment Effect

The FIC intervention was implemented over a nine month period, with the minimum number of contacts identified as once a month by telephone. In the post-intervention interviews, family caregivers identified that the maximum contact achieved with staff was six times during the nine month period. Throughout the period of the study the researcher felt that staff caregivers' commitment to the intervention was fragmented. This was despite their obvious interest during the education sessions and at times when negotiating the FIC agreement with family caregivers. It may be assumed that one of the most obvious factors associated with this lack of commitment is the dwindling numbers of RNs and the leadership they provide in ongoing support to unlicensed staff when engaging with families. Similar limitations to maximising the treatment effect have been encountered in the Maas et al. study and other intervention studies (Pillemer *et al.*, 2003).

Feasibility of the Intervention

This study aimed to implement an innovative partnership model of care in the residential aged care setting, with the view to applying the new knowledge gained from the research to change or improve clinical practice. Pearson (2004) maintains that for such an intervention to be translated to practice it must be shown that it is feasible; in other words it must be physically, culturally and financially practical. The study utilised a mixed method approach not only to test the effectiveness of the intervention, but also to provide evidence of its "appropriateness and meaningfulness" in the clinical environment through examination of the qualitative data collected (Pearson, 2004; p312). However, the findings show that in the current clinical environment of residential care it is not physically or culturally feasible to translate such an intervention and model of care into practice without sufficient and ongoing access to appropriately skilled and trained staff.

Similarly for family caregivers, meaningful involvement with staff begins with provision of knowledge about dementia and individualised care for their relative. Other research supports this experience, providing evidence that the effect of an intervention tends to be larger if it aims to increase the knowledge and skill of the family caregiver without considering psychosocial effects (Bartlett et al., 2007; Mittelman, 2008). Nevertheless, the mixed method, sequential two-phase design of this study allowed for analysis of the difference between short-term and long-term outcomes, and determined that there was some positive psychosocial impact on both family and staff well-being of ‘time to talk’ (Bower et al., 2003).

It is clear that family involvement in care is a multidimensional construct within a complex array of environmental influences (Gaugler, 2005a). This study highlights the difficulties in establishing a psychosocial intervention which will endure long enough to establish beneficial effects, in this instance positive change in stress and satisfaction levels. It also clearly identifies the challenges associated with implementing and testing an intervention in residential dementia care, particularly problems with participant attrition and sustaining the intervention over time (Gaugler, 2005a; Zarit & Femia, 2008).

In summary, the findings in this study suggest that due to structural workplace changes, minimal commitment from management and resource deficiency, there was a lack of staff caregiver ability to sustain the family-staff partnership at the intervention site. However, the validity of these conclusions is limited due to small sample sizes, family and staff caregiver attrition, and a lack of registered staff to provide leadership. Although there were some positive trends in the outcomes from increased involvement in care, few changes were identified in relation to stress for families as measured by *guilt*, *captivity* and *loss*. This is compared to the Maas et al. study outcomes in which beneficial effects were found for three of the four areas of family caregiver outcomes, and one in four of staff outcomes.

Implications for Future Research

This study has identified significant improvements in family knowledge of dementia at the intervention site, as well as some positive outcomes in terms of increased staff

knowledge about dementia and improved staff attitudes towards families. However it was difficult to determine the magnitude of the association between the partnership and improvement of the family-staff relationship due to the external influences associated with structural workplace changes and resource deficiency.

The Maas et al. research identified the difficulties implementing interventions in residential care as staff turnover, understaffing, the dominance of institutional regimes and lack of RN leadership (Maas et al., 2000). It is clear from this study that these difficulties are exacerbated if there is lack of ownership of the intervention by nurse management. Such difficulties hold little hope for future interventions if they are unable to achieve greater integration within the culture, environment and administration of RCFs. It was also found in this study that although the RNs and unlicensed staff received similar education in dementia care there was limited opportunity for engagement between them, and with families. Indeed staff adopted the view that the partnership with families was about families asking for help, thus increasing their perception of burden, rather than furthering a mutually beneficial collaborative arrangement. Further research is required to investigate ways of overcoming the dominance of the organisational culture and encouraging person-centred and client-centred approaches to care so that family-staff relationships can flourish for the benefit of all.

The family caregiver views and findings clearly support earlier family research and provide further evidence for the need in practice to build partnerships between families and staff, with the shared aim of providing for the therapeutic needs of the person with dementia (Gaugler & Ewen, 2005; Kellett, 2000; Maas et al., 2004; Woods et al., 2007). They also support the need in long-term care to develop a more systematic management approach to the integration of families in the residential environment, so that their roles and responsibilities are made explicit from the time their relative is admitted (Adams & Gardiner, 2005). Accordingly, a more developed relationship-based approach to care would ensure that clearer channels of communication are established between staff and families, with particular attention to the needs and experiences of the person with dementia (Adams & Gardiner, 2005; Adams & Moyle, 2007). Such a 'working in partnerships with families' approach would also encourage staff development and management involvement, with a focus on innovative multi-media and professional education programs tailored to dementia care (Beauchamp et al., 2005; Woods et al.,

2007). Future research is required to investigate family needs from a client perspective earlier in the dementia trajectory so that continuity of care and service delivery is established.

For staff caregivers the most significant finding was the increased stress observed at the intervention site due to the inappropriate behaviour of residents with dementia. This major source of stress has been identified in other recent studies, providing further evidence of the importance of inter-personal support from families and supervisors when caring for residents with dementia (Robinson et al., 2007). This finding also highlights the ongoing need to provide sufficient dementia-specific training and education within and across aged care settings so that consistency of support for staff is achieved (Cheek et al., 2003). Such education programs should also take into account the ethical issues associated not only with family caregiver roles but also with appropriate resource allocation to ensure best practice provision in dementia care (Brock, 2004; Woods et al., 2007).

In summary, this study emphasises the need for further research focused on family-staff partnerships with the approach that families themselves are clients and a potential resource for improving quality of care of the resident with dementia. The notion of client-centred care is not new and reflects the development of innovative approaches across the range of health care settings (Nolan et al., 2004). Within the family as client framework there is potential for the FIC protocol to be modified to target individual client groups, such as older and younger generation family caregivers (Maas et al., 2004; Mittelman, 2008). Because the design and theoretical framework of the study remains strong, it would be feasible to modify and further assess the impact of the intervention and partnership model of care across aged care settings and in individual client groups. As with the Maas et al. research, future research in Australia could then build on the existing framework to investigate new modes of health care delivery as a foundation to building client driven care, contributing to best practice and to the development of social and economic policy (Gordis, 2004; Maas et al., 2004).

CHAPTER 9

CONCLUSIONS AND RECOMMENDATIONS

Summary of the Research

During the past two decades there has been an increasing awareness in the aged care area of the importance of family involvement in care of the person with dementia. Although the major focus in Australia has been on implementing family programs in the community, for example CACPS, HACC and EACH, very little empirical research has been conducted on promoting family involvement in residential dementia care. This chapter highlights the major findings of this study and outlines conclusions and recommendations drawn from this work.

Transitioning to Residential Care

This study has confirmed that family caregivers do not experience relief from burden of care pressures when their relative is admitted to the new environment of residential care. This burden is compounded by a sense of isolation due to large and inappropriate facility design, lack of orientation to the facility and inadequate communication with staff. There is an expressed desire from families to increase their understanding and knowledge of dementia, the grief process and dementia care by establishing an ongoing relationship with staff members.

Promoting Involvement in Care

This study has highlighted the importance of sufficient orientation for family caregivers to the RCF, and validation from trained staff of their decision to place their relative in residential care. It is important that staff understand the impact of the long-term stressors on family caregivers associated with caring for the person with dementia at home, and their desire to continue to be involved in care. Families seek to establish a relationship with suitably trained staff so that they are prepared for the inevitable changes and complexities in their new caregiving role within the facility. Promoting an environment and culture that supports family involvement will provide the foundation for developing family-staff partnerships and improving care.

The sharing of knowledge about dementia and physical care of their relative with staff is only one aspect of the role of families in residential care. There is also family caregiver knowledge about the individual ‘person’ with dementia, their life history, personal needs and requirements. The family caregivers in this sample, many of whom are highly educated, have demonstrated an interest in becoming more actively involved with staff in making formal decisions about their relatives’ care. Their approach to involvement is from the ‘family as client’ perspective, enhancing care of their relative and providing an additional resource for staff. This approach emphasises the importance in residential dementia care of management commitment and a stable workforce educated in family involvement. For management, aspects of decision making in relation to care should be discussed with family caregivers so that changes in legal and ethical requirements are supported. For staff, by increasing their knowledge and understanding of the needs of family members, they can improve their ability to negotiate and fulfil their roles as caregivers and continue to improve evidence-based dementia care and service delivery.

The FIC Education Intervention and Partnership

Family caregivers identified the successes of the education and family-staff partnership as improvement in their knowledge about dementia, better communication with staff and increased personal benefits for their relative with dementia, such as increased engagement with staff and increased personalised activities. The major challenge highlighted by families was the detrimental effect of staff shortages and lack of trained staff to maintain such a therapeutic relationship.

It is clear that the potential also exists for family-staff partnerships to develop earlier in the trajectory of the disease, thus paving the way for more productive relationships as the dementia progresses. For staff, the benefits of working with families who are informed and at ease with their role translates to reduced role strain and care burden, with positive impacts for staff retention. Such interaction and engagement may also help reduce some of the obvious distress and burden of care for families, assist with them establishing an earlier diagnosis of dementia, and improve quality care outcomes for the person with dementia.

Staff and Family Stress and Satisfaction

Whilst the difficulties with measuring family and staff caregiver satisfaction have been raised in Chapter Eight, there is compelling evidence in the findings to suggest an inexorable link between the two. This study has provided further evidence that decreased family caregiver satisfaction may actually be a result of stress from increased knowledge about care alternatives. Similarly, staff who are dissatisfied are more likely to experience stress from their ineffectual relationship with families. These factors are compounded by a lack of staff education in dealing with residents with dementia, and lack of sufficient resources to meet their care needs.

Recommendations

Family Caregiver Involvement

This study has highlighted that family involvement in care can be promoted by ensuring that information and education for family caregivers is accessible, easier to understand, and suitable for client needs. It is important to complement the promotion of family involvement with ongoing staff education and training so that service providers match individual family caregiver resident needs with provision of informed choices in the residential care environment. It is recommended that such an approach could take into consideration improved knowledge of person-centred and relationship-centred care, therapeutic communication and negotiation skills, to reduce conflict between the person with dementia, the family caregiver and staff caregivers, and to also shift the dynamics in the triad such that families have equal input to decision making.

Staff Education

There is a call in aged care research and education for appropriate and clinically relevant staff education modules that provide improved scope of practice for dementia care staff and involvement of family caregivers. Packages of learning should be available so that they can be placed into tertiary programs or alternatively used as self-directed education. Such packages should be developed within the context of the dynamic and complex system of aged care.

More incentives are needed for health professional leaders to specialise in dementia care, such as scholarships and further education modules from specialist dementia staff education and training institutions, for example the Dementia Training and Study Centre. In these centres specialist trained staff provide avenues for development of

health professionals through the provision of university based undergraduate and postgraduate programs.

Family-Staff Caregiver Research

In order to extend aged care nurses' scope of practice it is recommended that:

- There is future and ongoing research to identify the key components of family-staff partnerships and to include this in the RN scope of practice;
- Evaluation of family-staff partnerships becomes part of ongoing staff and facility assessment. Skilled staff members are required to run the evaluation and interpret the results, and individual adjustments are made to become a part of standard care;
- Families are invited to work with staff to identify and shape interventions which are client driven, for example by providing personal accounts of caring for their relative with dementia;
- Intergenerational client groups are identified so that their specific needs, particularly those of spousal caregivers, may be more appropriately met. This would include family caregiver access to information through a number of different sources, eg books, leaflets, staff contact, Internet;
- A package of learning is developed on the impact of caregiver burden on families, including those specific to the Australian context, for example geographic isolation, the Australian culture of stoicism, the interface and flow of services;
- A package of learning is developed on staff-family partnerships, including negotiation, validation and advanced therapeutic communication skills, which link to the diagnosis, symptoms and behavioural problems associated with the different dementias.

Management Commitment

This study has emphasised that commitment from management and leadership styles that enhance a culture of acceptance to new models of care are critical to success. Similarly, a 'working in partnership' approach to family caregivers would also encourage staff development and management involvement, with a focus on innovative education programs tailored to dementia care. It is recommended that management in residential care develops an open culture of dementia care that supports families by

making transparent the current complaints procedures as a means to achieving continuous improvement. It is further recommended that, where possible, the education and therapeutic partnership with family caregivers is initiated at admission to residential care, before families establish a pattern of deference to staff, so the positive health benefits associated with the therapeutic exchange can be more easily established and maintained.

Dementia Care Research, Policy and Practice

It is clear that in Australia the provision of dementia care and service delivery is entering a new era in which innovative environments and models of care will develop that are focussed on client needs and continuity of care. More research is required that explores the benefits and limitations of different environmental designs, both for the person with dementia and family caregivers. Further longitudinal examination is also required of an intervention that can facilitate adjustment and role transition to reduce the adaptive problems associated with involuntary transition to care, and the stress and distress it causes. Such research would include examination of the social, economic and disease burden impacts on family caregivers of earlier assessment and diagnosis, earlier access to professional support and services, and the availability of client choice in making decisions about care.

It is recommended, therefore, that government invests in research that focuses on building productive, client driven partnerships in aged care, not only after but before the person with dementia is admitted to residential care. Indeed, the emphasis at policy level should be on providing family access to the therapeutic skills and knowledge of dementia care provided by specialist health professionals as soon after the diagnosis of dementia as possible.

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