

Current Experiences and Educational Preferences of General Practitioners and Staff Caring for People with Dementia Living in Residential Facilities

Qualitative Phase of the Dementia in Residential Care: Education Intervention Trial

Final Report
August 2009
Perth, Western Australia



© WA Centre for Health and Ageing 2009

An abridged version of this report has been published as: Beer C, Horner B, Almeida OP, Scherer S, Lautenschlager NT, Bretland N, Flett P, Schaper F & Flicker L. *Current experiences and educational preferences of general practitioners and staff caring for people with dementia living in residential facilities*. BMC Geriatrics, 2009. 9: 36.

Investigators

Dr Christopher Beer *Senior Lecturer, WA Centre for Health and Ageing*
Prof Barbara Horner *Director, Centre for Research on Ageing, Curtin University*
W/Prof Osvaldo Almeida *Professor of Geriatric Psychiatry, WACHA*
Dr Samuel Scherer *General Manager Medical Services, Royal Freemasons Homes of Victoria*
Prof Nicola Lautenschlager *Professor of Geriatric Psychiatry, University of Melbourne*
Dr Nick Bretland *General Practitioner*
Dr Penelope Flett *CEO, Brightwater Care Group (Inc)*
Frank Schaper *CEO, Alzheimer's Australia WA Ltd*
W/Prof Leon Flicker *Professor of Geriatric Medicine, WACHA*

Study Staff

Kelly Banz *Study Co-ordinator*
Dr Nada Eltaiba *Social Researcher*
Jenny Tasker *Research Assistant*
Geoff Jones *Dementia Consultant and Registered Clinical Psychologist, Silver Chain*

Acknowledgements

Funding by the NHMRC (Dementia Research Grant Program Strategic Award Grant 458797) is gratefully acknowledged.

The investigators and study staff acknowledge support from the WA GP Network who assisted recruitment of GPs and funded GP participation in focus groups, and RCF Staff and Divisional Staff who assisted with distribution of surveys.

Silver Chain, who supported secondment of Geoff Jones to the Study Staff

The study team would like to thank all participating GPs and RCF Staff, Divisional Staff, and Family Carers of people with dementia.

TABLE OF CONTENTS

LIST OF TABLES.....	4
1. ABSTRACT.....	5
BACKGROUND	5
METHODS	5
RESULTS	5
CONCLUSIONS	5
2. BACKGROUND	6
3. METHODS	9
3.1. <i>Quantitative Data Collection, Handling and Analysis</i>	9
3.2. <i>Qualitative Data Collection, Handling and Analysis</i>	10
3.3. <i>Ethical considerations</i>	11
4. RESULTS	12
4.1. <i>Quantitative Results: Current Knowledge and Participation in Dementia Education</i>	12
4.2. <i>Qualitative Results: Perceived Educational Needs and Preferences</i>	15
4.2.1. <i>Themes Related to Experience of Dementia (the “Dementia Journey”)</i>	16
4.2.2. <i>Themes Related to Dementia Care</i>	17
4.2.3. <i>Themes related to Barriers to Dementia Care and Education</i>	20
4.2.4. <i>Themes related to Facilitators of Dementia Care and Education</i>	21
4.2.5. <i>Themes related to Educational Content</i>	23
4.2.6. <i>Themes related to Educational Delivery</i>	26
4.2.7. <i>Unifying Themes</i>	28
5. DISCUSSION	29
6. CONCLUSIONS	32
REFERENCES	33
APPENDIX A-- DATA SOURCES AND MAJOR CATEGORIES OF DATA.....	36
APPENDIX B-- THEMES TO GUIDE DEVELOPMENT OF AN EDUCATIONAL STRATEGY	37
APPENDIX C-- EXPERT REFERENCE GROUP	37

List of Tables

Table 1 Demographics of Survey Respondents, and Perceived Current Knowledge of Dementia and Preferences for Dementia Education	13
Table 2 Characteristics of GPs attending RCF compared to those not attending RCF	14
Table 3 Summary of Participants in Individual Interviews and Focus Groups	15
Table 4 Themes related to the Experience of Dementia (the “Dementia Journey”)....	16
Table 5 Themes related to Dementia Care	19
Table 6 Themes related to Barriers to Dementia Care and Education.....	21
Table 7 Themes related to Facilitators of Dementia Care and Education	22
Table 8 Themes related to Educational Content	25
Table 9 Themes related to Educational Delivery.....	27

1. Abstract

Background Residential care is important for older adults, particularly for those with advanced dementia and their families. Education interventions that achieve sustainable improvement in the care of older adults are critical to quality care. There are few systematic data available regarding the educational needs of Residential Care Facility (RCF) staff and General Practitioners (GPs) relating to dementia, or the sustainability of educational interventions. We sought to determine participation in dementia education, perceived levels of current knowledge regarding dementia, perceived unmet educational needs, current barriers, facilitators and preferences for dementia education.

Methods A mixed methods study design was utilised. A survey was distributed to a convenience sample of general practitioners, and staff in 223 consecutive residential care facilities in Perth, Western Australia. Responses were received from 102 RCF staff working in 10 facilities (out of 33 facilities who agreed to distribute the survey) and 202 GPs (19% of metropolitan GPs). Quantitative survey data were summarised descriptively and chi squared statistics were used to analyse the distribution of categorical variables. Qualitative data were collected from general practitioners, staff in residential care facilities and family carers of people with dementia utilizing individual interviews, surveys and focus groups. Qualitative data were analysed thematically.

Results Among RCF staff and GPs attending RCF, participation in dementia education was high, and knowledge levels generally perceived as good. The individual experiences and needs of people with dementia and their families were emphasised. Participants identified the need for a person centred philosophy to underpin educational interventions. Limited time was a frequently mentioned barrier, especially in relation to attending dementia care education. Perceived educational needs relating to behaviours of concern, communication, knowledge regarding dementia, aspects of person centred care, system factors and the multidisciplinary team were consistently and frequently cited. Small group education which is flexible, individualized, practical and case based was sought.

Conclusions The effectiveness and sustainability of an educational intervention based on these findings needs to be tested. In addition, future interventions should focus on supporting cultural change to facilitate sustainable improvements in care.

2. Background

Dementia is estimated to affect 0.9% of Australians and is now the leading cause of non-fatal disease burden among older Australians. [1] [2] Prevalence is strongly age-related, with estimated prevalence rates of 6.5% in people aged 65 years and over, and 22.4% in people aged 85 years and over. [2] Australia has a complex system of community care provision, reflecting the preference of older people to remain in their own homes. [3] However, although most people with dementia are living in households (57%), many live in residential care facilities (43%). [2] Conversely, a large proportion of RCF residents have dementia (48%), and in fact this is the commonest medical problem affecting older people in residential care. [2] [4] Ninety-six per cent of people with dementia living in care accommodation in Australia have moderate or severe dementia, compared to only 7% of people with dementia living in households. [2] Informed residential care is thus important for older adults with dementia, particularly for those with advanced dementia, and their families.

Only a small proportion of beds (5% of low level care and 6% of high level care beds) are dementia-specific, and these usually have been designed to deal with specific behavioural and psychological challenges associated with dementia, such as frequent wandering or risky behaviours. These units are mainly wings and co-located units, rather than stand alone facilities. [5] The introduction of dementia programmes in mainstream Australian hostels is thought to have been effective in delaying transfer to higher level care and in improving quality of life.[6] However, unmet needs appear to be common among residents with dementia living in care facilities. [4] [7]

Many of the common challenges encountered in caring for people with dementia can be ameliorated. The behavioural and psychological symptoms of dementia (BPSD) are negatively associated with both carers' and patients' quality of life (QOL), and are thus an important target for interventions designed to improve QOL. [8] Systematic review of the available data found evidence for the efficacy of behaviour management therapies, educational interventions and possibly cognitive stimulation.[9] Behavioural treatments and non pharmacological interventions may reduce sleep and behavioural disturbances. [10] [11] [12] Likewise, there are data confirming that good quality care is associated with lower incidence of depression. [13] Changes to existing models of care, such as implementation of protocols to engage family caregivers, and environmental changes, may be effective in slowing residents' deterioration. [14] In addition, it has been possible to demonstrate that staff training and specialisation, and encouragement of activity participation, are associated with improvements in the quality of life of people with dementia living in residential care. [15] High quality care appears to benefit residential care staff as well as residents. Implementation of individualised nursing care plans has been shown to have a positive effect on nursing staff perceptions of burden and stress. [16]

Dementia is the most common problem managed by GPs at RCF consultations. [17] The ability of RCF staff and GPs to identify and respond to dementia is of critical importance. Training programs in dementia care for RCF staff are common and have been systematically reviewed. [18] However the evidence identified was mostly published in the United States, and frequent methodological weaknesses limited the

conclusions which could be drawn. There is little recent Australian data focusing on improving care delivery by workers in the residential care sector. A psychogeriatric team case management approach was not significantly more effective than a consultative approach or standard care in managing high level care residents with dementia complicated by depression or psychosis.[19] Moreover, our team found outcomes were no better when psychiatric team review was offered to people who screened positively for psychiatric morbidity on admission to residential care facilities.[20]

The available evidence suggests that education is effective in improving aspects of care delivery in residential facilities. Education of nursing assistants and ancillary staff improves their attitudes and knowledge regarding end of life care.[21] Training and support for nursing home staff is effective in reducing the proportion of residents with dementia who are prescribed neuroleptic medications (average reduction in neuroleptic use 19.1%; 95% confidence interval 0.5% to 37.7%).[22] A marked reduction in psychotropic prescribing in Sydney nursing homes occurred in line with educational interventions and publicity regarding inappropriate medication use.[23]

Available data suggest that under one in five GPs attend RCF. GPs attending RCF tend to be older and male. Dementia is the most common problem managed at RCF consultations, at 33 times the usual management rate in everyday practice. GPs attending aged care facilities deal with complex, chronic conditions (including dementia, stroke, and heart failure) which may be seen much more frequently than in everyday general practice. [17] The available evidence also suggests that despite recent initiatives to improve quality of care and facilitate access to GP services for RCF residents (including the Aged Care GP Panels Initiative, the Enhanced Primary Care program, and an expanded role of palliative care) many GPs still find RCF services unappealing due to a perceived poor level of remuneration for the effort involved. [24]

GPs in Australia are required to undertake Continuing Professional Development (CPD). To be eligible for CPD credit, activities must be prospectively approved, providing evidence of need, proposed objectives and evaluation, and reinforcing activities. Previous survey data showed that GPs have reasonable knowledge regarding dementia but that there were gaps in knowledge regarding diagnosis and management of dementia. [25] In addition to educational programs, assessment protocols were requested. Interestingly, GPs with better knowledge, and those with a greater proportion of consultations with older people, were more likely to seek further education. Therapeutic nihilism, desire to avoid risk, resourcing and competence have been identified as barriers to GPs participating in shared care models in the UK, and may also be relevant in Australia. [26]

The need to improve care of people with dementia living in residential facilities has been recognised and there has been a significant investment in dementia training in Australia through the 2005 Dementia Budget Initiative and other ongoing initiatives. However most of these initiatives have been aimed at specific groups of workers (such as Direct Care workers, or various health professionals) rather than multidisciplinary teams working in the same RCF. There are few systematic data regarding the content, sponsorship, access, incentives to participation, known barriers and cost of currently available dementia education in Australia. In addition, there is

also evidence that although there are many training programs currently offered, these do not necessarily meet the perceived needs of learners. The National Stocktake [27] of currently available dementia education collected data from providers and stakeholders using surveys and focus groups. There was a lack of standardization between courses and problems were identified with both content and delivery of educational programs. Costs (especially for lower paid workers) and staff shortages were barriers to learning. In addition, the currently offered courses often used didactic and inflexible teaching. This is at odds with the general consensus regarding the value of interactive learning methodologies. [28]

RCF staff (including professional and direct care staff) provides the bulk of day-to-day care for recipients of residential care who have dementia. GPs also play a key-role in the care of older people living in RCF, including collaboration in the development of management plans, prescription of medications and initiation of health referrals. Previous research suggests that RCF staff, General Practitioners (GPs) and family carers all play key roles in the care of older people living in Australian RCF. [14] [15] [23] As a result, interventions that aim to achieve sustainable improvement in the care of older adults with dementia living in RCF should take a multi-disciplinary team approach and include the GP, as well as RCF staff. There is a pressing need to determine whether an educational program, judged feasible in terms of time and cost, delivered to staff and GPs in the Australian residential care sector is effective.

The DIRECT study aims to determine if education of GPs and RCF staff can improve the quality of life (QOL) of people with dementia living in RCF. Our overarching hypothesis is that a systematic educational intervention delivered to GPs and RCF staff will improve care delivery, leading to measurable improvements in the quality of life of residential care recipients. We hypothesise that education delivered to GPs will have additive effects to education delivered to RCF staff. This paper presents the findings from the first stage of the DIRECT study, which collected qualitative data to inform development of a sustainable educational intervention for RCF staff and GPs based on the perceived needs and preferences of learners. The aims of the qualitative data collection were to:

- determine current participation in dementia education and perceived levels of current knowledge regarding dementia,
- determine barriers to and facilitators of improved dementia care,
- determine perceived educational needs relating to residential care for people with dementia,
- explore preferred methods of educational delivery, and
- understand participants' experiences of dementia care.

3. Methods

A mixed methods design, incorporating collection of both quantitative and qualitative data, was utilised.

3.1. Quantitative Data Collection, Handling and Analysis

A survey was distributed to GPs and RCF staff in metropolitan Perth. Questions were framed in relation to the study aims using a tick box design to collect basic demographic data (gender, age range and whether English spoken as a first language). RCF staff were also asked to indicate their role (Direct care, Clinical care, Support services or Management), number of years worked in aged care, number of residents cared for, and number of residents cared for with diagnosed or suspected dementia. GPs were also asked to indicate their Division and suburb, and whether or not they attended patients with dementia who are living in residential care facilities, and if so, how many. Respondents were asked to rate their current knowledge of dementia ('not good', 'good', 'very good' or unsure) and to indicate whether they had participated in dementia education programs and how they rated those programs ('not good', 'good', 'very good' or 'unsure'). Participants were asked to indicate their preferred method of delivery for educational programs (Workshops, Internet website, Poster, Booklet, Other).

A convenience sample (reliant on distribution of the survey by third parties) was used. An attempt was made to contact all multiple site aged care providers (41 providers providing care in 184 facilities) and single-site facilities (39) in the Perth metropolitan area, requesting to speak with the Manager or Director of Nursing. Providers and facilities who agreed then distributed the survey to their staff. Thirteen multi-site aged care providers and 20 single site aged care facilities agreed to distribute the survey. The survey was also sent to the six Perth metropolitan Divisions of General Practice (Canning, Coastal, Fremantle, Osborne, Perth and Hills, Rockingham), who in turn distributed the survey to all GPs on their registers (around 1050 GPs). Four Divisions distributed the survey by post and 2 Divisions distributed the survey by facsimile. Surveys were distributed between September and November 2007. The closing date for return of surveys was set 3 weeks after distribution by each Division.

All survey responses, including incomplete surveys, were collated. Not all respondents answered all fields, hence the total number of responses for some survey fields varied. Descriptive statistics were used to summarize the quantitative survey results. Pearson chi-square statistics was used to analyze categorical variables.

3.2. Qualitative Data Collection, Handling and Analysis

The surveys also utilised open ended questions to further explore current levels of knowledge, needs and preferences in relation to dementia education. Respondents were asked: ‘In what areas do you think you need more knowledge in relation to working with people with dementia?’; ‘What topics do you think should be included in an educational program for staff who are working with people with dementia?’; ‘What will be the barriers to participation in an educational program?’; and ‘Do you have any suggestions for the content of educational programs for GPs (or RCFs)?’. The survey was written in English and translations to other languages were not provided. Surveys were anonymous, but provision was made for GPs to record their personal details if willing to be contacted regarding participation in individual interviews or focus groups.

An Expert Reference Group (ERG) was formed (see appendix) comprising state and national experts in dementia care and dementia education. Terms of reference included identifying content and delivery methods for dementia education in residential care, and current barriers to education. Research staff kept a research journal recording any feedback received from Facility Managers regarding educational needs and preferences. This was collated and reflected upon during the study.

Individual interview and focus group guidelines were drafted and revised in light of the survey data and feedback from the ERG. Interviews and focus groups were conducted in care facilities, on university premises, or at participants’ offices or homes. The interviews and focus groups aimed to determine perceived unmet educational needs and preferred content and delivery of education. GP participants were recruited from survey responses. Invitations to participate in individual interviews and/or focus groups for staff and carers of people with dementia were distributed by facility managers and Alzheimer’s Australia WA. Carers of people with dementia were invited to share their own experiences, opinions and feelings (rather than acting as a proxy for the person with dementia). The interviews and focus group were facilitated by a social researcher with experience in mental health, training in conducting interviews and focus groups, and experience in qualitative research methodologies. The GP focus group was co-facilitated by a GP who has experience in dementia care.

Individual interviews, focus groups and meetings of the ERG were recorded and transcribed. Free text responses to the open ended survey questions, and notes made by study staff recording feedback from facility managers, were also transcribed. Transcripts were coded line by line. Codes were assigned relating to thematic content, and a sub-code could be assigned when required. In addition data were categorized according to whether they related to GPs, Family Carers, the RCF or RCF Staff, or the Person with Dementia. Initial coding of 13 transcripts was completed independently by the social researcher (who does not have specific experience in dementia care) and one of the authors (CB or BH, who are academic clinicians with experience in dementia care). This approach was prospectively chosen to minimise bias and support face validity of the qualitative analysis. Analysis continued until “saturation” (the qualitative researcher’s impression that no new themes are

emerging) occurred. A formal meeting was then held to review the initial individual analyses.

Consensus was reached regarding the emerging themes and sub-themes. The remaining data were independently coded by two people (the social researcher, and CB or BH). One coder then reviewed the two independent sets of codes, discussing any areas of uncertainty. Initial thematic analysis of final codes, by grouping of similar codes, was independently completed by two of the authors (BH, CB). A second formal meeting was then held to confirm consensus regarding the thematic analysis. A final thematic analysis was then drafted. Critical feedback was then sought from the remaining authors.

3.3. Ethical considerations

The Human Research Ethics Committee at the University of Western Australia approved this study (RA 4/1/1685). Each participant in focus groups and individual interviews provided written informed consent.

4. Results

4.1. Quantitative Results: Current Knowledge and Participation in Dementia Education

RCF staff returned 102 surveys. Ten RCFs returned an average of 10 surveys each. Determining the response rate is difficult for RCFs, as we relied on providers and facility managers to distribute the survey and did not confirm how many surveys were distributed. Responses were received from 30% of facilities who agreed to distribute the survey.

RCF staff respondents were most often female and in middle age groups. (Table 1) The majority (56%) worked in direct care or clinical care (24%) roles. The remainder worked in support services (15%), leadership and management (3%) or multiple (5%) roles. One in five of the respondents did not speak English as their first language. Although nearly half of respondents (46%) had less than five years experience, over one third (35%) was very experienced (having more than ten years experience). Twelve respondents (13% of those specifying gender) were male. Only five men answered the question regarding their first language, but 4 of those men said that English was not their first language. RCF respondents indicated that they cared for, on average, 52 residents. These data varied widely according to the facility type and the respondent's role. Respondents indicated that the majority of residents they cared for had either diagnosed or suspected dementia. On average, RCF staff reported that 70% of the residents they cared for had diagnosed or suspected dementia.

Three quarters of RCF staff who responded had attended some training about dementia. (Table 1) Nearly all rated such educational programs as 'good' or 'very good'. Furthermore, most respondents rated their current knowledge about dementia as 'good'. RCF staff preferred education to be delivered as a workshop. About a third of respondents indicated a preference for multiple delivery methods, usually workshop and booklet. Visual learning materials for display in common areas ("posters") were chosen infrequently. Preference of RCF staff for electronic delivery (Internet website, or Internet and another methodology) was infrequent and similar in staff aged less than 46 (n=5; 10%), and those aged 46 years and over (n=4; 8%; Chi=0.12, p=0.73).

GPs from all Divisions responded to the survey, returning 202 surveys. Nineteen per cent of Perth GPs responded to the survey. Men and women were approximately evenly represented. (Table 1) One in five of the GPs who responded indicated that they did not speak English as their first language. Most GPs were older, and accordingly, most GPs who responded were very experienced (only 19% has less than 11 eleven years experience). More than half of the GP respondents (57%) did not currently care for people with dementia living in residential care facilities. For those that did care for people with dementia living in RCF, the average case load was 21.

Just over half (57%) of the GPs who responded had not attended an educational program in dementia. (Table 1). While most (67%) said their level of knowledge regarding dementia was “very good” or “good”, a surprisingly high percentage (25%) said that their knowledge was “not good”, and a further 8% were uncertain. Workshops were the preferred method of delivery. Another popular option was workshop with booklet. Although a preference for Internet based delivery was more common than among RCF staff, the majority still preferred workshop based delivery. GPs aged 45 years and younger were more likely to indicate a preference for electronic delivery of education (Internet website, or Internet and another methodology, n= 26, 34%) compared to older GPs (n=18, 17%, Chi=7.25, p<0.01). GPs who had not participated in an educational program were less likely to report “good” or very good’ perceived knowledge (n = 58, 52%) compared to GPs who had participated in an educational program (n= 72, 86%, chi= 19.37, p<0.001).

Table 1 Demographics of Survey Respondents, and Perceived Current Knowledge of Dementia and Preferences for Dementia Education

	RCF STAFF N= 102 N (%*)	GP N= 202 N (%*)
<i>Gender Female</i>	83 (87)	89 (45)
<i>Aged</i>		
25 years and under	5 (5)	0 (0)
26 to 35 years	10 (10)	18 (9)
36 to 45 years	37 (37)	63 (32)
46 to 55 years	26 (26)	65 (33)
56 to 65 years	22 (22)	43 (22)
66 years and over	1 (1)	11 (6)
<i>English as first language</i>	83 (82)	157 (81)
<i>Self-rating of knowledge about dementia</i>		
Very good	38 (38)	19 (10)
Good	49 (49)	112 (57)
Not good	11 (11)	49 (25)
Not sure	3 (3)	16 (8)
<i>Have attended a dementia education program</i>	80 (78)	86 (43)
<i>Rated that program</i>		
Very good	40 (51)	19 (23)
Good	36 (46)	57 (70)
Not good or not sure	2 (3)	6 (7)
<i>Preferred delivery method</i>		
Workshop	61 (62)	107 (57)
Internet website	2 (2)	13 (7)
Poster	0 (0)	0 (0)
Booklet	3 (3)	12 (6)
Workshop + Internet website, poster, or booklet	29 (30)	50 (27)
Other	3 (3)	6 (3)

* not all respondents answered all questions

GPs who responded to the survey and were attending RCF tended to be older, and were more often male, than GPs not attending RCF (52% of male respondents reported attending RCF, compared with 32% of female respondents). Age specific proportions of GPs reporting caring for people with dementia in RCF were: 35 years and less, 22%; 36-45 years, 23%; 46-55 years, 55%; and 56 years and over, 59%. GPs attending RCF were more likely to have attended an educational program and to perceive their knowledge as good or very good. (Table 2)

Table 2 Characteristics of GPs attending RCF compared to those not attending RCF

	ATTENDS RCF N (%)	DOES ATTEND NOT RCF N (%)	STATISTIC	P
<i>Male Gender</i>	57 (66%)	51 (46%)	Chi=8.443 Df=1	0.004
<i>Age</i>				
<55	55 (63%)	91 (81%)	Chi=7.47 Df=1	0.006
56+	32 (37%)	22 (19%)		
<i>English as first language</i>	69 (82%)	88 (81%)	Chi=0.062 Df=1	0.803
<i>Rate Knowledge</i>				
VG or good	68 (80%)	63 (57%)	Chi=11.73 Df=1	<0.001
NG or unsure	17 (20%)	48 (43%)		
<i>Have Participated in Dementia Educational Program</i>	53 (62%)	33 (29%)	Chi= 20.483 Df=1	<0.001

Chi = Pearson Chi squared; Df= degrees of freedom; VG = 'very good'; NG = 'not good'

4.2. Qualitative Results: Perceived Educational Needs and Preferences

In addition to open ended survey questions, qualitative data were available from individual interviews with 6 family carers, 5 GPs and 4 RCF staff; focus groups of 4 family carers, 9 GPs and 7 RCF staff, two meetings of the ERG and feedback recorded from 10 facility managers. Characteristics of participants in individual interviews and focus groups are shown in Table 3. There were 1829 individual codes. (Table 4) Most codes (780; 43%) were from GPs. Similar quantities of data were available from family carers (483 codes; 26%) and RCF staff (482 codes; 26%). Remaining data were from the ERG and feedback recorded from facility managers (84 codes; 5%).

Table 3 Summary of Participants in Individual Interviews and Focus Groups

DATA SOURCE	PARTICIPANT GROUP	NUMBER	AGE GROUPS	GENDER	OTHER INFORMATION
Individual Interviews	GPs	5	1 25-35 1 40-50 3 50-60	3 men 2 women	2 identified as being from culturally diverse backgrounds
	RCF Staff	4	3 20-30 1 40-50	4 women	1 supervisor, 3 carers
	Family Carers	6	3 50-60 2 60-70 1 70-80	1 man 5 women	4 partners of PWD 2 children of PWD 3 visited weekly, 3 daily One identified as being from NESB
Focus Groups	GPs	9	1 <35 3 36-45 3 46-55 2 56-66	4 women 5 men	
	RCF Staff	7		7 women	4 supervisors 1 CN 1 EN 1 Carer
	Family Carers	4	2 40-50 2 60-70	3 men 1 woman	2 partners of PWD 2 children of PWD

4.2.1. Themes Related to Experience of Dementia (the “Dementia Journey”)

Data from families emphasised the individual path of people with dementia and their loved ones:

‘I think overall that each case is so different and people you’re dealing with are so different’ (Family carer)

Family carers commonly described the dementia journey in negative terms, focusing on disempowering feelings (such as loss, uncertainty and bewilderment) in relation to both their own experiences, and their perceptions of their relative’s experiences:

‘I just thought she was going a bit vague and bit old age a bit confused, a bit daft’. (Family Carer)

‘He’s losing himself, he says I’m losing the person who’s me and this gives you an insight into how they must be feeling and how frightened they must be. They must be very frightened’ (Family Carer)

‘It’s left me with nothing’ (Family Carer)

To some extent these negatives themes were counterbalanced by positive descriptions of aspects of the dementia journey. Positive themes included the strengths of the person with dementia and their family carers, and the learning which occurs as part of the dementia journey:

‘But I keep saying to them ... he’s still got part of his brain is still good. He recognised me’ (Family Carer)

‘It’s taken you quite a while to learn what we learnt and we can still learn’ (Family Carer)

Table 4 Themes related to the Experience of Dementia (the “Dementia Journey”)

CATEGORY (NUMBER OF CODES)	THEME (NUMBER OF CODES)	SUB-THEMES (NUMBER OF CODES), WHEN SPECIFIED
Family’s Journey (78)	Disempowerment (48)	Bewildering (3) Denial (2) Desperation (1) Dislocation (1) Distress (10) Escape (1) Exhausting (1) Futility (1) Grief (1) Guilt (1) Helplessness (1) Hopelessness (2) Inevitability (1) Invisibility (1) Isolation (3) Lack of knowledge (1) Loss (3) Separation (3) Suffering (1) Uncertainty (8)
	Engagement for PWD (3)	Boredom (2)
	Learning (12)	Resources (2)
	Strengths (8)	Acceptance (2) Humour (1) Perverserance (2) Support (2) Survivor (1)
	Symptoms (2)	Recognition (2)

	Person Centred Care (2)	Individualised (1) Personal History (1)
	Costs (3)	Personal (1)
Person with Dementia's Journey (84)	Awareness (12)	Diminished (3)
	Behaviours (5)	
	Learning (2)	Community services (1) Diagnosis (1)
	Disempowerment (36)	Bewildering (3) Illness (1) Infantilisation (1) Isolation (1) Denial (1) Dissatisfaction (1) Loss (22) Progression (2) Risk (1) Restraint (1) Uncertainty (1)
	Diversity (2)	
	Strengths (5)	Acceptance (1)
	Symptoms (12)	Lack of knowledge (1) Relentless (5)
	Transitions (6)	Environment (1) Loss (1) Residential Care (1) Separation (1)
	Person Centred Care (4)	Communication (1) Personal History (1)

Data Source: 162 Codes, all (100) from Family Carers. PWD= people with dementia.

4.2.2. Themes Related to Dementia Care

Participants felt that education relating to dementia and dementia care should be underpinned by a clear guiding philosophy. In this respect participants asserted the importance of individualised, respectful person centred care as the foundation of educational interventions. A person centred approach was seen as facilitating high quality dementia care. Participants emphasised that a flexible approach, with a focus on understanding the personal history of the resident, facilitated care delivery.

Understanding dementia as a “journey” was felt to facilitate individualised, person centred care and indicated the importance of changing needs:

‘I think it’s a misnomer and I think it’s a misleading issue too this whole thing of stages, it makes us think that there is, think in stages and there aren’t, I mean people are just on a journey’ (ERG member)

Although negative aspects of care were emphasised, including the indignities and costs of dementia care in personal terms, sentiments of appreciation for care delivery predominated:

‘She is strapped into the wheelchair during the day’ (Family Carer)

‘Well it’s the strain; it’s the strain of going in. It’s not only your partner; you’re seeing all the others as well’ (Family Carer)

‘I think they’re marvellous, really marvellous and of course the more often you go you become part of the whole community in a way’ (Family Carer).

'I think she has actually in some ways improved since she has been in there probably because of the caring and the attention and also the company' (Family Carer)

Participants accepted that most people delivering care are usually well intentioned but emphasized the importance of leadership in the provision of quality care:

'The staff are doing the best they can but some of the, of the wives they get very upset about these things that go missing' (Family Carer)

'it depends enormously on the person who is in charge, the main RN or whatever it is in those places because like anything else so much depends on the leadership as to how the team works and whether the people feel happy or not' (Family Carer)

Participants also asserted the importance of individualised, respectful person centred care.

'and this woman said that T's been "a very naughty boy" I mean this is just not on, this kind of patronizing way of saying to a (laughs) a man in his seventies you know, anyway.....this is one of the difficulties isn't it of (um) of caring for people with dementia because they are fully grown adults so you've got to give them the kind of respect due to an adult' (Family Carer)

'every individual is different and their behaviours are differentthey can't understand that they're two different people even though they've got the same disease' (RCF Staff member)

In addition to the need to recognize the individual needs of people with dementia, the diversity of staff and facilities was emphasised:

'You have a team of people and they've got different talents or you recognize that some of them are rather short tempered or some of them are too self effacing' (Family Carer)

'more and more we're seeing African and Asian people coming into the industry. There's a lot of different viewpoints depending on which side of, which culture are you standing.' (RCF Staff member)

Specific care issues focused on in the data included caring for people with behaviours of concern, engagement of people with dementia, medication management and communication:

'...behaviour is there, they have to just work with and accept it. Acceptance is a big issue I think. Whatever you see and whatever is displayed in front of you, you have to accept it, you can't change it' (RCF Staff member)

'they don't have much stimulation for the residents' (Family Carer)

'Just kept feeding her is it 'Serepax' and or sleeping tablets and things'
(Family Carer)

'Anytime that they inform me about anything regarding my wife is if she has a fall out of the wheelchair or out of her bed' (Family Carer)

'they can improve by communicating with the families, have a meeting with the families' (Family Carer)

'the GP is obliged to keep all information confidential but that leaves the other family members at a loose end, they don't know. I don't see how you can get around it' (Family Carer)

Table 5 Themes related to Dementia Care

THEME (NUMBER OF CODES)	SUB-THEMES (NUMBER OF CODES), WHEN SPECIFIED
Acceptance (7)	
Appreciation (37)	Physical Environment (2)
Behaviours (6)	Personal items (1)
Care Role (13)	Advocacy (3) Monitoring (2) Practical help (1) Sharing (1) Support (1) Transitions (1)
Communication (60)	Conferencing (5) Family involvement (1) GP- Family (2) Inadequacy (6) Non verbal (8) Partnerships (1) RCF Staff – Family (5) GP Anonymous (1) Participation (1)
Dementia Knowledge (9)	Diagnosis (8) Prevention (1)
Diversity (19)	Care standards (1) Client needs (1) Physical Environment (1) Residents (1) Staff (7) Staff – Age (1) Staff – Race (1) Training needs (1)
Engagement for PWD (14)	Boredom (1) Family involvement (1)
Environment (3)	Homeliness (1) Relaxing (1)
Indignity (23)	Bewildering (1) Infantilisation (2) Institutionalisation (1) Personal items (3) Roughness (1) Separation (2) Uncertainty (1)
Individualised care (6)	Flexibility (1) Fluctuation (1) Personal History (1)
Leadership (7)	Advocacy (1)
Medication management (8)	Adverse effects (1) Futility (1) Overuse (5)
Multidisciplinary team (8)	Team work (8)
Person Centred Care (64)	Awareness (1) Community (2) Compassion (1) Continuity (18) Dignity (1) Holistic (1) Individualised (3) Intimate (1) Language (7) Non judgemental (1) Nurture (4) Patience (3) Personal History (4) Physical health (2) Wellbeing (1)
Cultural Factors (9)	Language (4) RCF Avoidance (4) Staff (1)

Workforce (12)	Absenteeism (1) Inadequacy (1) Staff Ratios (9) Time (1)
Costs (3)	Financial Implications (1) Personal (2)

Data Sources: 308 Codes in total, 12 (4%) from the ERG or Facility Managers, 262 (85%) from Family Carers, 1 (<1%) from General Practitioners and 33 (11%) from RCF Staff

4.2.3. Themes related to Barriers to Dementia Care and Education

Participants identified multiple barriers to the provision of quality dementia care and education. System factors, including the complexity of aged care and workforce factors were frequently emphasised by participants. System factors ranged from local matters, such as appointment and review systems to more universal issues such as the available funding:

‘It’s very frustrating. Our worst is sitting in the hairdressers and you can’t see them because the hairdresser’s more important’ (GP)

‘funding again does not allow us to have that one person trained’ (RCF Staff member)

Participants viewed a range of work force issues as potential barriers. These included medical workforce shortages and rapid turnover of staff in residential care facilities:

‘What concerns me a bit is that a lot of the young GPs they really don’t seem to be terribly interested in it’ (GP)

‘But with the attrition of staff leaving the industry, so new people coming in and people moving on that you’re constantly having this uphill battle of educating your staff’ (RCF Staff member)

Conflicting interests between workforce groups were also cited as barriers to best practice:

‘often the knowledge is there about which drugs you can use and how and you know to avoid too much medication but it’s just that you either don’t get told, or you can’t do behavioural management - all they want is something to knock ‘em out’ (GP)

Lack of communication was frequently mentioned as a potential barrier, for example when lack of communication allows incorrect expectations to persist:

‘nobody tells them that you know this person’s going to be one of twenty or one of eighty or one of however many and so perhaps there needs to be more education of the carers, the home carers prior to admission to residential care so that when they get there they don’t expect that one on one’ (RCF Staff member)

Time was a frequently mentioned barrier, especially in relation to dementia care education:

'I suppose time more than anything else, that's from my perspective, I would have thought it's just finding the time to get it [education]' (GP)

Table 6 Themes related to Barriers to Dementia Care and Education

THEME (NUMBER OF CODES)	SUB-THEMES (NUMBER OF CODES), WHEN SPECIFIED
Communication (7)	Client Information (1) GP (2) RCF Staff – Family (1) Confidentiality (1) RCF Staff – GP (1) RCF Staff – Hospital (1)
Complexity of care (20)	Lack of knowledge (2) Overwhelming (2) Futility (1) Stress (1)
Leadership (4)	Organisational culture (1) Organisational readiness (1) Clear Expectations (1)
Task oriented approach (5)	
Time (15)	
System Factors (17)	Appointments (1) Documentation (1) Funding (8) Remuneration (4) Under recognition of importance (2)
Cultural Factors (11)	Language (7) Generation gap (1) Meals (1)
Workforce (21)	Diversity (1) Inadequacy (2) Reluctance of GP to visit (1) Medical Staffing Model (1) Staff Ratios (6) Staff shortages – Ageing (1) Staff training (1) Staff turnover (1)

Data Sources: 100 Codes in total, 12 (12%) from the ERG or Facility Managers, 14 (14%) from Family Carers, 34 (34%) from General Practitioners and 40 (40%) from RCF Staff.

4.2.4. Themes related to Facilitators of Dementia Care and Education

Several potential barriers were also identified as facilitators. This suggests that some of these particular barriers may be avoided or overcome. These included communication, workforce issues and system factors.

'You've got to be, have a happy approach when you go to these people' (RCF Staff member)

'It's got to be good team work. Yeah, it has to be and it's got to be twenty four hour team work, not seven hours' (RCF Staff member)

'I think if you run your, your individual practice sensibly and you do regular comprehensive medical assessments then you can make it pay as well' (GP)

'The issue of in hours and after hours carethere needs to be organisational changes to support doctors in the care that they provide, although that's not specifically an educational role' (GP)

Management leadership was cited as a potential facilitator of cultural change in residential care:

‘I think the biggest gap has come from the fact that quite often the care staff go and learn this information and they’ll usually really enjoy it when they’re at the course. When they come back into their environment, and it’s set up in such a way that the culture’s so hard to change because you almost need your higher management people to also understand that there needs to be the flexibility and all that kind of stuff as well’ (RCF Staff member)

A person centred approach was seen as facilitating high quality dementia care. Participants emphasised that a flexible approach, with a focus on understanding the personal history of the resident, facilitated care delivery:

‘Just knowing about what’s happened around them and being aware of what reality they are in by knowing the history of what happened during that time, is of assistance and letting the resident talk and tell his or her story’ (RCF Staff member)

‘But it’s having the flexibility and flexibility within the area you’re working is important. And the understanding of the people managing those areas, that flexibility is needed as well’ (RCF Staff member)

Table 7 Themes related to Facilitators of Dementia Care and Education

THEME (NUMBER OF CODES)	SUB-THEMES (NUMBER OF CODES), WHEN SPECIFIED
Communication (6)	Acceptance (1) Cheerful approach (1) Family involvement (1) Non verbal (1) Personal (1) Positive (1)
Leadership (4)	Empowerment (1) Flat organisational structure (1) Cultural Change (1)
Medication management (1)	Medication Reviews (1)
Resources (3)	Access to specialist services (1) GP Divisions (1) For families and PWD re services (1)
System Factors (3)	Access to specialist services (1) After hours support (1) Remuneration (1)
Person Centred Care (10)	Intellectual challenges (1) Personal History (2) Dementia Specific (1) Flexibility (4) Care planning (1)
Workforce issues (5)	Staff training (1) Time management skills (1) Team work (2) Peer support (1)

Data Sources: 32 Codes in total, 0 (0%) from the ERG or Facility Managers, 1 (3%) from Family Carers, 12 (38%) from General Practitioners and 19 (59%) from RCF Staff.

4.2.5. Themes related to Educational Content

Data from all sources provided evidence of a need for improved knowledge of aspects of dementia and dementia care.

'I wish I'd known more when I was actually caring for T myself. To have more understanding of how exhausted he must have been trying to put everything together in his head' (Family Carer)

'Well when I came, when I first started working here it was, it's frustrating for me and it's frustrating for the residents if you don't have any knowledge' (RCF Staff member)

'It would be really good to get a neurologist who was interested in dementia and the assessment and early treatment of dementia to talk to GPs because I mean. I don't think we ever get that opportunity unless it's sponsored by your 'Aricept' or Galantamine or one of the drug type companies' (GP)

There was also recurrent emphasis on the need for education regarding assessment and care planning, both at the level of care staff, and professional staff

'education on what, how to identify what the actual resident's need is, would be a good one' (RCF Staff member)

'assist both the GP and the nursing home how to coordinate their two care plans. Because each of them is coming at a plan from a different direction, under different regulations' (GP)

In addition to knowledge based education regarding dementia itself, GPs and care staff identified education relating to other common health problems in people with dementia as being important. These included mental health issues, skin problems, pain and continence.

'Well the other aspect of skin is that you get an awful lot of your skin cancers that aren't going to be operated on that are to being left and so for some docs it may be useful going over some of the newer creams and stuff that they could have a go at where you're doing a sort of very passive approach to some of these tumours' (GP)

Person centred care was also seen as an important focus of education:

'It's not task oriented, it's not focused on giving care to a person, it's about that person and them, and to me if we can get the role in the education right, what we're fostering is that attitude and that's when you get this transformation of change.' (ERG Member)

'And actually looking past the actual disease and seeing the person' (RCF Staff member)

Other important considerations included palliative approaches to care and the legal framework for care:

'the whole negotiation of end of life type preparation, and also about at what point do you say to a family, this is sort of an end of life type issue.' (GP)

'that's actually the legal aspects of when someone is capable of determining a Will. When they are legally responsible for making their own decisions. What the guardianship board involves and how they go about it' (GP)

Behaviours of concern were consistently cited as an area of particular importance:

'understanding that you're not going to change the behaviour. The behaviour is there, it's not going to go away tomorrow or the next day. It's the way you work alongside with that behaviour that the resident is displaying' (RCF Staff member)

Communication, similarly, was frequently identified as being of central importance. Communication issues related to inter-professional communication, communication with people with dementia, and also communication with family carers:

'How to handle family. How to work with the family as well because they're often very distressed and in fact I've often times started a grieving process because they've lost their husband or their father already, even though he's not physically gone' (RCF Staff member)

'So for example somebody who has a chest infection and they've got dementia, how do we set up the planning and the meeting with families so that the best decisions are made in terms of the care of the patient' (GP)

There was some variation in preferred educational content for families, GPs and RCF staff. For example, RCF staff identified a need for education in strategies to engage people with dementia, and regarding leadership in aged care facilities, more often than GPs. GPs cited issues relating to medication management and legal issues more frequently than RCF staff (see table 8).

Finally there were pragmatic requests for resources and education to assist people with dementia, families and workers in negotiating various aspects of the aged care system. An example is the interface between the residential and acute care systems:

'The other day I had a patient who needed intravenous antibiotics; I had no idea how to go about it. So I was speaking to people at the hospital and I phoned, I don't know how many people I phoned. I phoned about twenty people to find out how to get what do they call it, 'help at home' to come. It's not really help at home, there's a Department that does intravenous care and they could come out to the Lodge to do that. But I had to phone about twenty different people to get to that point' (GP)

Table 8 Themes related to Educational Content

CATEGORY (NUMBER OF CODES)	THEME (NUMBER OF CODES)	SUB-THEMES (NUMBER OF CODES), WHEN SPECIFIED
Educational Content for Family Carers of People With Dementia (25)	Communication (2)	End of life care (1) GP (1)
	Dementia Knowledge (15)	Empowerment (1) Stages (2) Symptoms (1) Treatment Options (2) Types (1) Community Awareness (3) Behaviours (1)
	Engagement for PWD (1)	
	Multidisciplinary team (2)	GP role (1) Staff training (1)
	Resources (1)	Support groups ineffective (1)
	System Factors (1)	Referral (1) RCF Services (1)
	Person Centred Care (1)	Compensating (1)
Educational Content for RCF Staff (355)	Assessment (8)	Pain (1)
	Behaviours (84)	Aggression (13) Anger (1) Antecedents (1) Common patterns (e.g. sundowners) (1) Flexibility (1) Impact on staffing (1) Individualised (1) Pathophysiology (1) Preventing escalation (2) Recognition of reasons (1) Treatment Options - Reality and validation therapy (1) Variation (1) Disorientation (1)
	Care planning (4)	Best practice guidelines (1) CMA (1) Documentation (1) Legal (1)
	Communication (54)	Family - Education (1) Family conferencing (1) Family involvement (2) GP-RCF staff (1) RCF Staff – PWD (5) Non verbal (8) RCF Staff – Family (9) Continuity (1)
	Co-morbidities (5)	Mental health issues (1) Pain (2) Continence (2)
	Complications (12)	Falls (3) Pressure sores (3) Sleep (2) Swallow (4)
	Dementia Knowledge (57)	3 Ds (2) Aetiology (1) Demographics (2) Diagnosis (2) Knowledge update (2) Pathophysiology (8) Severe (1) Specialisation (1) Stages (10) Symptoms (2) Types (5) Younger onset (2) Ageing Physiology (2) First aid (1) Prevention (1) Research update (6)
	Engagement for PWD (20)	Cognitive stimulation (1)
	Individualised care (5)	Flexibility (1) Need for dementia education across RCF staff (1)
	Leadership (16)	Cultural change (11) Organisational change (3) Organisational culture (1) Sustainability (1)
	Medication management (12)	Polypharmacy (1)
	Multidisciplinary team (6)	Combination of experiences (1) GP liaison (1) GP referrals (1) Role of nurse practitioners and practice nurses (1) Team building (1)
	Palliative approach (3)	
	Physical health (4)	Activity (2) Preventing decline (1)
	Resources (3)	Community services (1)
	Staff self care (10)	Assertiveness training (1) debriefing (1) Recognising capacity to cope (1) Self respite (1) Time management (3)
	Treatment options (8)	Complementary therapies (3)
	System Factors (7)	Acute Care (1) Industry input to DoHA (1) RCF services (1) Referral (2) Staff Ratios (2)
	Person Centred Care (36)	Avoiding task oriented work practices (1) Communication with PWD (1) Dignity (1) Experience of dementia (2) Holistic (1) Independence (1) Journey (1) Meeting needs (1) Not task oriented (1) Organisation readiness audit (2) Resident needs management (1) Respect (1) Understanding needs (2) Family (3) Personal History (2) QoL (2) Environment (1)
Cultural Factors (2)	Cultural safety (1) Multilingual delivery (1)	
Educational Content for GPs (663)	Assessment (19)	
	Behaviours (68)	Aggression (1) Therapy (3) Restraints (7)
	Care planning (11)	Best practice guidelines (3) CMA (3) Co-ordination (1) Templates (1)
	Communication (44)	Case conferencing (5) Family involvement (1) GP-Family (26) GP-PWD (1) RCF Staff (2) Family (5) Family - Psychological support (1) RCF staff- GP referral criteria (1)
	Co-morbidities (22)	Constipation (1) Gastro (1) Intellectual disability (1) Management (1) Osteoporosis (1) Other neurodegenerative conditions (1) Pain (4) Parkinson's (1) Psychiatric (2) Skin (2) Continence (3)

Complications (14)	Falls (2) Infections (2) Sleep (2) Swallow (3) Wound Care (5)
Dementia Knowledge (97)	3 Ds (10) Aetiology (2) Demographics (1) Diagnosis (34) Investigations (3) Pathophysiology (1) Early Recognition (4) Screening (1) Stages (3) Types (8) Ageing Physiology (1) Common problems (4) Ethics (2) Prevention (4) Research update (3) Symptoms (3)
Engagement for PWD (2)	
Legal (16)	EPOA (4) Guardianship (2)
Medication management (96)	Adherence (1) Advanced old age (2) Adverse effects (2) Individualised (1) PBS (1) Polypharmacy (1) Role of cholinesterase inhibitors (1) Withdrawal (3)
Multidisciplinary team (27)	Agency staff (1) Allied Health (1) Care models (1) Delegation to achieve holistic care (1) GP support for RNs (2) Roles (1)
Palliative approach (10)	Advanced Care planning (3) Spirituality (1)
Physical health (5)	Activity (1) Maintenance (1) Nutrition (1)
Resources (112)	ACAT (1) Allied Health (1) Dental services (2) Handbook (1) Interpretation services (1) Local (2) RCF manual (1) Resources directory (6) Template Care plans (1) Tool box (1) Traps and pitfalls (1) Practical Guides (2) RCF Staff Guides (1) Specialist Access (1)
Self care (2)	Avoiding burnout (1) Time management (1)
Transitions (8)	Benefits (culturally appropriate) (2) Life expectancy (family beliefs) (1) Necessity (1) Reluctance (1)
Treatment options (59)	Complementary therapies (1) Psychiatric (1) Social (1)
System Factors (31)	Accreditation (1) Acute Care (3) Allied Health (2) Community resources (1) External factors (1) Funding (9) GP role (1) RCF admission criteria (1) RCF services (1) Referral (7) Regulatory framework (1) Remuneration - MBS items (1)
Person Centred Care (12)	Awareness (2) Holistic (1) Psychosocial (3) Values base (1) Individualised (1)
Cultural Factors (5)	Culturally specific education (5)

Data Sources: 1043 Codes in total, 23 (2%) from the ERG or Facility Managers, 43 (4%) from Family Carers, 663 (64%) from General Practitioners and 314 (30%) from RCF Staff.

4.2.6. Themes related to Educational Delivery

Participants emphasized the diversity of needs among both residential care staff and general practitioners, suggesting flexible, modular approaches to educational delivery. Participants emphasised the need to ensure educational interventions are sustainable. The need for individualized approaches related not only to prior learning, but also to individual preferences for educational delivery.

'I think it needs to be a tiered approach, targeting people with little or no knowledge. Those with some and those with sort of a reasonable level and being able to up-skill' (RCF Staff member)

'It depends on the person, it depends on what they want themselves.' (GP)

Some participants suggested that external contributors were important in determining the curriculum for educational interventions:

'I'm always acutely aware that we don't know what we don't know sometimes and there is something to be said for leaving some aspects of the education policy up to the educators themselves' (GP)

Participants, both GPs and RCF staff, generally favoured small group, interactive learning with a focus on opportunities for mentoring. Case based learning was suggested for both face to face group learning, and for electronic delivery.

'I think if you do give the people the opportunity to brainstorm solutions for their own problems they're usually very good. The care staff, particularly the ones who are really interested in finding answers to the problems themselves' (RCF Staff member)

'if they can use case studies, so real case studies, information about people and how their dementia's progressed and some of the behaviours or problems or difficulties in meeting their care needs and how they overcome those' (RCF Staff member)

'It needs to be a relatively stable group, they need to meet regularly and what makes it good is it's more personal, people get to know each other - there'll also be an element of provision of support as well.' (GP)

'I always think of these videos as being very similar to small group experience and it's what I call battle stories, you know when you get together with your mates and talk about a bizarre case that occurred, listen to other people's bizarre cases and the odd sort of lateral thinking that their colleagues have used to solve them' (GP)

Table 9 Themes related to Educational Delivery

CATEGORY (NUMBER OF CODES)	THEME (NUMBER OF CODES)	SUB-THEMES (NUMBER OF CODES), WHEN SPECIFIED
Delivery of Education to Family Carers (1)	Large group (1)	Lectures (1)
Delivery of Education to GPs (73)	Electronic (12)	Case based (2) Online Database (1) Online Videos (1) Small groups - online lectures (1) Video lectures (3)
	Experiential (3)	Clinic (1) RCF rounds (1) Seminars with geriatrician (1)
	Individualised (9)	OTDs (2) Resources targeted to new GP (1) RPL (5)
	Large group (4)	Lecture (4)
	Mentoring (7)	Access to specialist services (1) One on one (1) Special interest eg legal (1)
	Self directed (3)	Reading (1)
	Small group (22)	Case based (3) Group meetings (1) Interactive (2) Lunch meetings (1) peer facilitation (1) peer review (1) Mentoring (1) Workshops (5)
	Education Framework (12)	Brief (1) Sustainability (1) CPD (2) Cross curricular (1) Implementation (1) Joint delivery

		RCF and GP (1) Locally relevant (1) Problem based (1) Specialist Driven (1)
Delivery of Education to RCF Staff (110)	Electronic (5)	Case based (1) Visual aids (2)
	Experiential (7)	Disability simulation (1) Non text book (1) Practical experience (1) Role plays (1)
	Individualised (13)	Learning styles (2) Novel delivery and materials (1) RPL (4) Staff Goals (1) Suite of delivery methods (1)
	Leadership (4)	Involve management (1) Organisational readiness (2)
	Mentoring (27)	Benchmarking (2) Champions (4) Debriefing (1) Deliver to RNs (1) Dementia reference group (1) Participative, follow-up (1) Peer brainstorming (2) Practical application (2) Sustainability (1) Tool box (1) Workplace support (1)
	Self directed (3)	
	Small group (16)	Case conferencing (3) Facilitated Modules (1) Family conferencing (1) Problem solving (1) Case conferencing (2)
	Time (2)	
	Person Centred Care (1)	Best friends model (1)
	Education Framework (32)	Case based (1) Sustainability (9) Hard copy (2) Implementation (1) Joint delivery RCF and GP (3) Locally relevant (2) Modular (3) Orientation (2) Problem based (1) Educational standards (1) Evidence based (1) Implementation (6)

Data Sources: 184 Codes in total, 37 (20%) from the ERG or Facility Managers, 1 (<1%) from Family Carers, 70 (38%) from General Practitioners and 76 (41%) from RCF Staff.

4.2.7. Unifying Themes

Unifying themes were found consistently and frequently in the qualitative data from each participant group, and across the survey, interview and focus group data. Behaviours of concern, communication, dementia knowledge and person-centred care were important to all groups of respondents. The importance of organisational factors such as support for effective multidisciplinary teamwork, communication and leadership were also consistently emphasized. However variability in experiences and needs across the sector were also emphasised, highlighting the importance of an individualized approach and identifying local barriers and solutions.

The data allow conclusions to be drawn regarding the preferred framework, content and delivery of an educational strategy to improve dementia care in Australian residential care facilities. These findings are presented in Table 11. In addition the data inform decisions regarding prioritisation of content and ongoing organisational support for training RCF participants.

5. Discussion

Study participants supported the goal of providing high quality care which focuses on the individual needs of people with dementia. In fact, several participants explicitly endorsed provision of care which is “person centred”. [29] Thus the study findings accord with the currently available guidelines regarding care delivery in residential facilities. It is reassuring that not only is participation in educational opportunities high, but respondents working in and attending RCF generally perceived themselves as having good levels of knowledge regarding dementia. However, given the high prevalence of dementia in Australian RCF, the fact that 20% of RCF staff do not have specific dementia training is concerning. A quarter of GPs indicating that their knowledge is “not good” is also of concern. Perhaps some of these GPs care for small numbers of older people. However GPs caring for few older people are likely to become increasingly scarce given the ageing of our population. It will be difficult for those GPs to provide leadership in diagnosis and clinical care for people with dementia if their knowledge is limited. Other GPs may hold nihilistic attitudes.

The survey data tend to confirm anecdotal perceptions of increasing diversity in the aged care RCF workforce. The proportion of people reporting that English is not their first language (18%) appears higher than in the general Western Australian population (of which only 13% reported speaking a language other than English at home in the 2006 census). This heterogeneity may present challenges in the design of future educational interventions.

Findings of our study are consistent with the available evidence, which frequently identifies limited resources and staff turnover as barriers to education in residential care. [28] Despite staff turnover being noted as a barrier in the qualitative responses, over one third of RCF staff who responded to the survey were very experienced (more than ten years) indicating a stable core of staff who may be targeted by educational interventions. Our results are also consistent with work showing that GPs commonly cite managing behaviour, communication and system factors (such as co-ordination of support service) as areas of concern, and time, lack of resources and nihilism as barriers to good care. [30] [31] Several potential barriers to improved care were also identified as facilitators in our data. This suggests that these factors may be avoided or overcome. These included communication, workforce issues and system factors. Interestingly, successful improvements in the quality of care have not necessarily been accompanied by marked improvement in the knowledge of care providers, or increases in their perception of the quality of care of care delivered. [32] Similarly, improved staff knowledge does not necessarily translate to improved care outcomes. [33] These findings are consistent with our data, which suggests that although knowledge *per se* may be important, problem solving, teamwork and communication skills will be critical components of successful interventions to improve the care of people with dementia. The data thus emphasise the need for future work to determine the best ways to support sustainable cultural change in residential care facilities and to allow facilities to identify and overcome local barriers to improved care. Organisational audit may be a useful tool for sites to identify local problems and assess their readiness for change.

Our respondents generally favored delivery of education in workshops, or workshops combined with other educational methodologies. These findings challenge the presumption that electronic methods of delivery will become increasingly popular. Generally, face-to-face workshops with a range of other educational methodologies have been the basis of effective educational interventions. [34] In contrast, education which relies simply on the provision of information may not be effective. [35] Further data are required to determine whether a preference for face-to-face delivery is because on-line methods have been found to be ineffective, or because they have not been trialed. Our findings, including preferences for multi-disciplinary training (shared between RCF staff and GPs), support the design of other proposed dementia training programs. [36]

To our knowledge this is the most comprehensive effort to understand perceived knowledge of dementia care in residential settings in Australia, and to identify the perceived factors relevant to improving care. The process of recruiting RCFs and GPs for this study was intense and multi-faceted. It required frequent and personal communication, as well as regular follow-up. There was neither shortage of interest in the study, nor any question of its importance or the value of the findings in determining an education intervention. However the business of RCF and GP practices presented many operational challenges that impact on the ability of individuals to participate in the study. In addition to RCF staff and GPs, family carers play a key role in the care of people with living in RCF. [14] Including the opinions of family carers increases the likelihood that the data are reliable and generalisable. [15] In addition to the multiple sources of data, the strong critical review process ensures that the data have face validity and increase the likelihood that the data are representative and externally valid. Consistency of themes between data from various sources (survey, focus groups and interviews) indicate that the data collected are internally valid and appear adequate in relation to the aims of the study.

Survey respondents were widely distributed geographically which increases the likelihood of representativeness of the sample. Results may be affected by volunteer bias. For example, newer staff (especially those who do not have strong English language skills) may be less likely to respond to surveys or volunteer to participate in interviews and focus groups. Staff perceiving their knowledge as good may be more likely to respond. The pattern of demographic characteristics of GPs attending RCF in our sample, compared to GPs who do not attend RCF, mirrored national data. Nationally, GPs attending RCF were more likely to be older and male (20% of male GPs attend RCF compared with 15% of female GPs; and 10% of GPs aged less than 35 years attend RCF compared with 12% of those aged 35-44 years, 20% aged 45-54 years and 22% aged 55 years or more). [17] This supports validity and representativeness of our survey sample. Despite this similarity in the pattern of demographic characteristics between our sample and the national data, the proportion of GPs attending RCF in our sample was higher than in the national data-set, suggesting a volunteer bias. GPs attending RCF may have been more likely to participate in our study. The proportion of GPs reporting participation in dementia education appears to be higher in our sample than in other overseas surveys which used more purposive sampling strategies. [37] Again this may reflect volunteer bias in our sample, rather than true differences.

Although the survey was comprehensively distributed, interpretation of the survey data is limited by the response rate. A limitation of the study was the absence of reminders or provision of a mechanism for follow up of surveys which were not returned. Preserving confidentiality was of high importance, making follow-up logistically challenging. The sampling strategy employed was considered the most feasible of the available options, but may have missed some potential participants (such as GPs who are not members of a Division). However these numbers are likely to be small. Our survey results should also be regarded with caution as the survey instrument has not been validated. We only measured perceived knowledge and did not validate respondents' perceived knowledge (such as by including knowledge based questions). Several other limitations warrant consideration. The survey was only distributed in English, and focus groups and interviews were only conducted in English. Whilst this would be less likely to be problematic for GPs and professional staff working in care facilities, it may have been a barrier to participation in the study for care staff. We did not distinguish accredited from unaccredited education session and this could be relevant to the quality of educational programs participated in, particularly for GPs, where a formal accreditation process is in place for continuing professional development activities.

A summary of themes to guide development of an educational strategy is suggested in Appendix B.

6. Conclusions

RCF staff and GPs attending RCF work together and frequently participate in dementia education programs, and current knowledge is perceived as good. However, many identify a gap in their knowledge and seek better understanding of how to provide quality care. Thus future educational interventions should be carefully designed to maximize engagement of all these groups. Interventions that facilitate learners assessing their prior knowledge and building on that foundation may be most likely to add value. Future educational interventions may need to be flexible to meet the needs of an increasingly heterogeneous and multicultural residential aged care workforce.

An educational strategy for RCF staff and GPs which is flexible, case-based, locally relevant and focused on practical strategies is most likely to meet the perceived needs of learners. Educational interventions need to consider sustainability, such as by identifying, nurturing and supporting local champions and leaders. Options for joint education of GPs and RCF staff should be provided. An educational program needs to include emphasis on the philosophy of care, and equipping participants with relevant skills, in addition to improving knowledge relating to dementia and dementia care. The study data emphasise the need for interventions that focus on sustainable cultural change in RCF. The next stage of the DIRECT study will be to develop, implement and evaluate an educational intervention using these findings.

References

1. Australian Institute of Health and Welfare (AIHW), *Older Australia at a glance 2002 (3rd edition)*. Vol. AIHW Cat. No. AGE 25. 2002, Canberra: AIHW & DOHA.
2. Australian Institute of Health and Welfare, *Dementia in Australia: National data analysis and development*, in *AIHW cat. no. AGE 53*. . 2006, AIHW: Canberra.
3. Henderson, E.J. and G.A. Caplan, *Home sweet home? Community care for older people in Australia*. *J Am Med Dir Assoc*, 2008. **9**(2): p. 88-94.
4. Rosewarne, R., et al., *Care needs of people with dementia and challenging behaviour living in residential facilities: resident profile survey*. Aged and Community Care Service Development and Evaluation Reports, Working Paper 1. 1997, Canberra: AGPS, Commonwealth Department of Health and Family Services.
5. Australian Institute of Health and Welfare (AIHW), *Older Australia at a glance 1999 (2nd edition)*. Vol. AIHW Cat. No. AGE 12. 1999, Canberra: AIHW.
6. Rosewarne, R., A. Bruce, and M. McKenna, *Dementia programme effectiveness in long-term care*. *Int J Geriatr Psychiatry*, 1997. **12**(2): p. 173-82.
7. Hancock, G.A., et al., *The needs of older people with dementia in residential care*. *Int J Geriatr Psychiatry*, 2006. **21**(1): p. 43-9.
8. Shin, I.S., et al., *Neuropsychiatric symptoms and quality of life in Alzheimer disease*. *Am J Geriatr Psychiatry*, 2005. **13**(6): p. 469-74.
9. Livingston, G., et al., *Systematic review of psychological approaches to the management of neuropsychiatric symptoms of dementia*. *Am J Psychiatry*, 2005. **162**(11): p. 1996-2021.
10. McCurry, S.M., et al., *Nighttime insomnia treatment and education for Alzheimer's disease: a randomized, controlled trial*. *J Am Geriatr Soc*, 2005. **53**(5): p. 793-802.
11. Lichtenberg, P.A., et al., *Pilot study of behavioral treatment in dementia care units*. *Gerontologist*, 2005. **45**(3): p. 406-10.
12. Woods, D.L., R.F. Craven, and J. Whitney, *The effect of therapeutic touch on behavioral symptoms of persons with dementia*. *Altern Ther Health Med*, 2005. **11**(1): p. 66-74.
13. Mann, A.H., et al., *Depression and the response of residential homes to physical health needs*. *Int J Geriatr Psychiatry*, 2000. **15**(12): p. 1105-12.
14. Jablonski, R.A., D. Reed, and M.L. Maas, *Care intervention for older adults with Alzheimer's disease and related dementias: effect of family involvement on cognitive and functional outcomes in nursing homes*. *J Gerontol Nurs*, 2005. **31**(6): p. 38-48.
15. Zimmerman, S., et al., *Dementia care and quality of life in assisted living and nursing homes*. *Gerontologist*, 2005. **45 Spec No 1**(1): p. 133-46.
16. Berg, A., U.W. Hansson, and I.R. Hallberg, *Nurses' creativity, tedium and burnout during 1 year of clinical supervision and implementation of individually planned nursing care: comparisons between a ward for severely*

- demented patients and a similar control ward.* J Adv Nurs, 1994. **20**(4): p. 742-9.
17. O'Halloran, J., H. Britt, and L. Valenti, *General practitioner consultations at residential aged-care facilities.* Med J Aust, 2007. **187**(2): p. 88-91.
 18. Kuske, B., et al., *Nursing home staff training in dementia care: a systematic review of evaluated programs.* Int Psychogeriatr, 2007. **19**(5): p. 818-41.
 19. Brodaty, H., et al., *Randomized controlled trial of different models of care for nursing home residents with dementia complicated by depression or psychosis.* J Clin Psychiatry, 2003. **64**(1): p. 63-72.
 20. Kotynia-English, R., H. McGowan, and O.P. Almeida, *A randomized trial of early psychiatric intervention in residential care: impact on health outcomes.* Int Psychogeriatr, 2005. **17**(3): p. 475-85.
 21. Parks, S.M., et al., *Evaluation of an educational program for long-term care nursing assistants.* J Am Med Dir Assoc, 2005. **6**(1): p. 61-5.
 22. Fossey, J., et al., *Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial.* Bmj, 2006. **332**(7544): p. 756-61.
 23. Snowdon, J., *A follow-up survey of psychotropic drug use in Sydney nursing homes.* Med J Aust, 1999. **170**(7): p. 299-301.
 24. Gadzhanova, S. and R. Reed, *Medical services provided by general practitioners in residential aged-care facilities in Australia.* Med J Aust, 2007. **187**(2): p. 92-4.
 25. Brodaty, H., et al., *General practice and dementia. A national survey of Australian GPs.* Med J Aust, 1994. **160**(1): p. 10-4.
 26. Iliffe, S., J. Wilcock, and D. Haworth, *Obstacles to Shared Care for Patients with Dementia: A qualitative study.* Fam. Pract., 2006. **23**(3): p. 353-362.
 27. Consulting, A.C.E.a. *Stocktake of Continence and Dementia Workforce Curricula, Education and Training Project Final Report.* October 2006 [cited 2009 13 April 2009]; Available from: <http://www.bladderbowel.gov.au/ncms/projects/workforcesupport/dementiacontinence.htm>.
 28. Nolan, M., et al., *The role of education and training in achieving change in care homes: a literature review.* Journal of Research in Nursing, 2008. **13**(5): p. 411-433.
 29. Kitwood, T., *Person and process in dementia.* International journal of geriatric psychiatry, 1993. **8**(7): p. 541.
 30. Turner, S., et al., *General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia.* Age Ageing, 2004. **33**(5): p. 461-7.
 31. Olafsdottir, M., M. Foldevi, and J. Marcusson, *Dementia in primary care: why the low detection rate?* Scand J Prim Health Care, 2001. **19**(3): p. 194-8.
 32. Chodosh, J., et al., *Effect of a dementia care management intervention on primary care provider knowledge, attitudes, and perceptions of quality of care.* J Am Geriatr Soc, 2006. **54**(2): p. 311-7.
 33. McCabe, M.P., T.E. Davison, and K. George, *Effectiveness of staff training programs for behavioral problems among older people with dementia.* Aging Ment Health, 2007. **11**(5): p. 505-19.
 34. Downs, M., et al., *Effectiveness of educational interventions in improving detection and management of dementia in primary care: cluster randomised controlled study.* Bmj, 2006. **332**(7543): p. 692-6.

35. Waldorff, F.B., et al., *Implementation of a clinical dementia guideline. A controlled study on the effect of a multifaceted strategy*. Scand J Prim Health Care, 2003. **21**(3): p. 142-7.
36. Perry, M., et al., *Can an EASYcare based dementia training programme improve diagnostic assessment and management of dementia by general practitioners and primary care nurses? The design of a randomised controlled trial*. BMC Health Serv Res, 2008. **8**: p. 71.
37. Cahill, S., et al., *Dementia in primary care: the first survey of Irish general practitioners*. Int J Geriatr Psychiatry, 2006. **21**(4): p. 319-24.

Appendix A-- Data Sources and Major Categories of Data

SOURCE OF DATA	MAJOR CATEGORIES OF DATA	EXPERIENCE OF THE DEMENTIA JOURNEY	EXPERIENCE OF DEMENTIA CARE	BARRIERS TO DEMENTIA CARE AND EDUCATION	FACILITATORS OF DEMENTIA CARE AND EDUCATION	DELIVERY OF DEMENTIA EDUCATION	EDUCATIONAL CONTENT	TOTAL NUMBER OF CODES
ERG and Feedback from Facility Managers	Experiences and Needs of GP's					4	3	7
	Experiences and Needs of People with Dementia		10					10
	Experiences and Needs of RCF Staff		2	12		33	20	67
Family Carers	Experiences and Needs of Family Carers	78	30			1	24	133
	Experiences and Needs of GP's		48	9			3	60
	Experiences and Needs of People with Dementia	84						84
	Experiences and Needs of RCF Staff		184	5	1		16	206
General Practitioners	Experiences and Needs of GP's			31	12	69	654	767
	Experiences and Needs of RCF Staff		1	3		1	9	13
RCF Staff	Experiences and Needs of GP's		1	4			3	8
	Experiences and Needs of RCF Staff		32	36	19	76	310	474
Total Number of Codes		162	308	100	32	184	1043	1829

Appendix B-- Themes to guide development of an educational strategy

Principles of Educational Framework	Flexible Delivery Sustainability Options for Joint Delivery between GPs and RCF Staff Locally Relevant Implementation (“how to” strategies) Leadership Case or Problem Based
Educational Content Themes	Care Philosophy and “Caring for Carers” Behaviours of Concern and Engagement for PWD Communication and Staff Approaches System Factors and the Multidisciplinary team Assessment, Care Planning, Palliative Approaches and Legal Aspects Dementia Knowledge (including Treatment Options, Complications and Co-morbidities) and Resources Medication management
Educational Delivery Modes	Individualised – range of methods including self directed Small group mentoring and experiential learning facilitated Time Efficient Electronic options available

Appendix C-- Expert Reference Group

Dr Sam Davis *School of Rural Health, Monash University*
 Nina Graham *Project Coordinator, WA Dementia Training Study Centre*
 David Gribble *Manager, Education, Alzheimer’s Australia WA*
 Geoff Jones *Dementia Consultant and Registered Clinical Psychologist, Silver Chain*
 Bruce MacAdam *General Manager, McCusker Learning*
 Virginia Moore *Dementia Consultant, Brightwater Group*
 Pam Nichols *Alzheimers Australia WA*
 Ashley Osborne *Quality and Access Projects Officer, Aged Care, WA GP Network*