Personal and Possible:

Achieving Quality Dementia Care

in Residential Aged Care Services

APPENDICES

Alzheimer's Association Australia

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APPENDIX 1 : Research process

Qualitative case studies were used to gather in-depth information about the care environment and practices contributing to the quality of life of persons who have dementia. Three Australian residential aged care services were selected for these observations. The intent of this approach was to optimise understanding of quality care and the structural factors required to enable quality of care to be replicated.

1 ETHICAL CONSIDERATIONS

The study adhered to guidelines set by the Alzheimer's Association of South Australia Research Ethics Committee. The conduct of the study follows the NH&MRC Guidelines for informed consent, ensuring free participation and withdrawal at any time. Participants were offered the opportunity to review and provide feedback on sections of the draft report that related to their facility.

2 SELECTION OF RESIDENTIAL AGED CARE SERVICES

Three Australian residential aged care services were purposefully selected to provide the informational needs of the study. To enable breadth of study each of the three services were located in a different State – one each in New South Wales, South Australia and Victoria. The residential aged care services were required to have received at least one commendable rating in the accreditation process. Selection of residential aged care services was made on the basis of the accreditation report available in the Executive Summary of the Assessment Team's Report in relation to the Decision to Accredit and with recommendations of experts in the aged care industry. Coincidentally, all of the three were dementia units. Dementia care units have tended to care for those who are physically strong amd have behavioural difficulties, but is noted that more currently there has been a blurring between the type of resident in dementia units and those in residential aged care services generally.

3 DATA COLLECTION AND ANALYSIS

Intensive fieldwork occurred over an average of four days in each residential care site. Fieldwork explored the following broad areas of care:

ext of care:	• Environment, including people • Structure and management of the facility • Philosophy/values/paradigm
ess of care:	• Culture/model • Practices
ome of care:	• Quality of life of residents with dementia, their family significant others • Quality of working life of staff and volunteers.

Data was gathered by

- in-depth semi-structured interviews of key people within each facility
- focus group interviews were held with family and friends of residents and with volunteers
- informal discussions with staff
- collection of documents and brochures.

A focus group comprising of health professionals from aged residential and community care including members of the Quality Standards Advisory Committee, discussed the findings and their implications, contributing to the final Discussion section.

A Fieldwork Schedule was developed for each facility and included day and late evening observations.

FIELD STUDY PROGRAM: SITE A

	ity
24 Oct 2001	of facility liarisation with systems and structures
6 Nov 2001	iew DON
9 Nov 2001	nation session and discussion with staff ssion with team leaders
2 Jan 2001	Dne rvation and informal discussions kfast period through to early afternoon nal discussion with Team Leader and PCAs
3 Jan 2001	Two rvation and informal discussions, with family, residents and PCAs iew with Care Coordinator and Unit Team Leader noon and evening
8 Jan 2001	rvation of program in the recreation area Observation of volunteers participation in music and dance, beauty thera program Interview volunteer Interview with daughter Discussion with son Roast lunch with residents and daughters Informal discussion with daughters, RNs and PCAs

FIELD STUDY PROGRAM: SITE B

	ity
ec 2001	liarisation
ec 2001	w and discuss program of unit rvation – volunteer morning tea nal discussion with volunteers iew RN rvation and informal discussions with ENs, care workers, support staff rvation of evening meal rvation of evening sensory / relaxation program
ec 2001	w of systems, structures s group with volunteers s group with family and friends of residents rvation of lunch period iew with DON rvation and informal discussions – particular focus on resident responses
ec 2001	w of documentation and systems rvation and informal discussion throughout the day – talking with staff abou ning behind their actions nary meeting

FIELD STUDY PROGRAM: SITE C

	ity
ct 2001	ing with DON/Manager to discuss project and program for field study iew volunteer iew DON/Manager ribe design of unit – observation during evening
ct 2001	rvation during morning nal discussion DON/Manager rded interview with Spiritual Care facilitator rve SONAS (Community support worker) iew with Community Coordinator iew of with aromatherapist rvation during afternoon iew with personal care attendant s group: family members
ct 2001	rvation midday and evening nal discussion w of documentation
ct 2001	rvation throughout day nal discussions
ct 2001	nary meeting

APPENDIX 2 : Profile of the residential aged care services

The descriptive overview that follows presents features of each residential aged care services. While the study was to identify quality care, rather than compare sites, the information below shows the variability of a range of factors.

SITE A

Number of residents:	
Residents in dementia unit:	Jnit : 15 (and 2 respite) gh level care: 2 Low level care ıd Unit : 12 all high level care
Unit staffing structure:	work in teams. Each team has a leader. Staffing levels Unit 1 ng 1staff person from 7am-3pm; 1staff person from 8am-4pm n leader); 1staff person from 8am-12.30pm: afternoon 1 staff n from3.30-11pm; 1staff person from 4.30-8.30pm. Team bers have specific areas of responsibility, e.g. infection contro al handling, lifestyle, etc.
Accreditation commendable ratings:	gement Systems, Staffing and Organisational Development: h and Personal Care: Resident Lifestyle.

The field study included 2 Units of residents. The building was some thirty years old but its design suited its purpose. Each unit had a centrally located kitchen, lounge and dining room with residents' rooms in adjoining wings. Resident rooms were single with ensuite. Décor was comfortably elegant and homelike. This site utilised large numbers of volunteers who assisted with activities.

SITE B

Number of residents:	
Residents in dementia unit:	ll High level care
Unit staff:	overs nursing home and dementia unit, staff work betwee ınits. Unit Staffing levels for morning 1staff person for8hrs person for6hrs: afternoon 1staff person for 8hrs; 1staff pe ırs. Staff worked cooperatively in teams and individual sta specific areas of responsibility.
Accreditation commendable ratings:	gement Systems, Staffing and Organisational Developme h and Personal Care.

There had been recent major building developments at this site with the dementia unit being the newest addition. The design of the new building minimised the institutional feeling and created a homelike environment. Rooms were single with ensuite and residents were encouraged to personalise their room with their photograph on the door.

This service had the advantage of being located in a supportive rural community and it was not uncommon for people entering the facility to be known to the staff. Under new leadership, the service has undergone significant organisational change and had moved from a deficit to viability over a 2 year period.

Site C

Number of residents:	
Residents in dementia unit:	of 13, 6 in one section, 7 in the other.
	gh level care: 1 Low level care
Unit staffing:	ger/DON was the only RN in the facility. Staffing levels
	ng and afternoon 1 personal care attendant each side bu
	needed they work together. Staff with special functions e
	ıal care and activities coordination come into the unit.
Accreditation commendable ratings:	gement Systems, Staffing and Organisational Developme
	h and Personal Care.

This site, opened in 1990 was a purpose built unit, with two separate but adjoining sections. Residents were able to move between the two sections and the garden. Each had its own kitchen, dining area and lounge. Residents' rooms were large, some single and some shared. The furnishings and décor were reflective of a home environment.

Appendix 3 : Excerpt from Quality Dementia Standards (UK)

Look at these first ...

Section 1
Person-centred care

1.1
An understanding and knowledge of dementia

1.2
Understanding the concept of person-centred care

1.3
Using life history

1.4
Communicating with people with dementia

1.5
Enabling choice and participation

1.6
Person-centred language

... then these ...

Section 2
Staff

2.1
Staff training and development

2.2
Staff supervision

2.3
Working together as a team

2.4
Effective management

Section 3
Care processes

3.1
Moving in

3.2
Assessment and care planning

3.3
Monitoring and reviewing care

3.4
Managing risk

... then these

Section 4
Life in the home

4.1
Activity

4.2
Materials, equipment and resources

4.3
Personal care

4.4
Eating and drinking

4.5
Outdoor activity

Section 5
Relationships

5.1
Maintaining important relationships

5.2
Supporting relationships within the home

5.3
Relationships with the resident's family and friends

5.4
Sexuality and intimacy

Section 6
Environment

6.1
An enabling environment

6.2
Personalising the environment

6.3
Privacy

Source: Quality Dementia Care in Care Homes : Person-Centred Standards, Alzheimer's Society, UK

Appendix 4 : A case study

The following precis gives a case example of an incremental change process toward person-centred care.

In 1994 the Bradford Dementia Group (UK) were contracted to conduct training in a new charitable nursing home which was to have a significant dementia care component.

The assumption was that training and development will impact on staff attitudes and beliefs, knowledge and skills, thus affecting interactions of staff and residents and subsequent resident quality of life. Two tools were used for objective assessment: one for staff attitudes, knowledge and skills and one for resident well being (DCM).

The new care home was purpose build in 1995 with 50 beds and award winning design. The building was separated into two units, one for physically frail and one for people with dementia. Both units were then split into two 'villages' of 12-14 residents. There were homelike furnishings, gardens, communal and quiet rooms, and single rooms with ensuite.

The initial assessment showed a number of issues:

- staff rotated between the two units, affecting continuity and relationships with residents
- senior staff had not been trained in supervision with no induction program or in-service in place
- the organisation of the staff was hierarchical with staff meetings infrequent and problem focused
- initial dementia care mapping showed interaction of staff and residents focussed primarily on physical not psychological needs
- there were few activities based around resident's interests and preferences with missed opportunities to involve residents in day to day activity
- work was organised mainly around convenience for staff e.g. bath rotation.

A 3 phase implementation strategy reviewed 6 monthly occurred.

Phase 1:
2 day training for senior staff
2 day training for direct care staff

Senior managers developed an action plan including e.g.

- establishment of supervision protocol
- development of life history documentation
- development of care planning practices
- involvement of relatives in home.

Outcome
Observations following training showed an increase in staff awareness with increased interactions with residents as measured by DCPA. There was little change shown in resident well being from DCM exercise.

Phase 2
Feedback on mapping exercise was given to staff and an action plan was drawn up e.g.

- staff would engage residents in more activities
- more attention to residents unable to express their needs or in distress
- rotation of staff phased out
- appointment of p/t nurse development practitioner
- leadership responsibilities clarified.

Outcome
Staff were choosing significantly more person centred responses. DCM showed positive changes in care values but not in the well being of residents.

Phase 3
Action plan from feedback was developed e.g.

- increase variety of physical activities available to residents
- increase sensory stimulation
- encourage independence where possible
- give cues around lunch time and involve in preparation
- communication philosophy more.

Outcome
DCM finally began to show improvements in residents' well being.

Summary: Two further 6 month action plans after training were required to affect resident well being. Without the organisational and management context, the potential effectiveness of training is diminished.

Lintern T & Woods B Before and after training: a case study of intervention, *Journal of Dementia Care*, Jan / Feb 2000

Lintern T & Woods B, Training is not enough to change care practice, *Journal of Dementia Care*, March / April 2000

Appendix 5 : Person-centred care

Excellent surroundings, arrangements, safeguards, and routines do not guarantee people who have dementia the correct care to meet their individual needs (Williams, 1997). A person-centred culture of care is well documented as being necessary (Kitwood, 1995; Fares 1997; Zimmermann 1998; Tolson, Smith et al. 1999; Dewing 2000). A person-centred approach goes far beyond simplistic notions of individualised care, it represents a fundamental shift of philosophy in caring practices (Ford, 2000).

According to Kitwood (1995) there are two intimately mixed ingredients at the heart of person-centred care: an ethic and a social psychology. The ethic asserts all human beings have absolute value and we thus have an obligation to treat each other with deep respect. While the ethic might provide a motive, practical insight and skill to do the task well would be lacking. Social psychology has no in-built ethic but provides a body of knowledge that shows how people with dementia can live out their lives in the most fulfilling way. Only when the ethic and social psychology are brought together does person-centred approach come into being.

A person-centred approach to care practice recognises the 'lived experience' of the person. Good dementia care is centred on the person who has dementia and affirms their personhood (Goldsmith, 1999) and is necessary for well being.

The Brightwater Care Group Inc has identified person-centred care as having the following10 key points:

- attend to the whole person with a positive and proactive approach
- each person is seen as special and unique
- respect of and knowledge of the past
- focus on abilities not disabilities
- maintain and nurture communication at the feeling level
- nourish attachments and create community
- care and respect for staff
- maximise freedom, minimise control
- don't just give, allow yourself to receive as well
- cognition does not determine the ability to experience well
- cognition does not determine the ability to experience well being and ill being.

Dementia Care Mapping

Dementia Care Mapping (DCM) (has emerged as a validated audit tool in assessing the quality of care of people with dementia in formal care settings. It has developed from a person centred approach. The methodology involves observing between 5-10 participants continuously over a set period, classifying observations on a 6 point behaviour scale of ill-being – well-being. DCM also observes Personal Detractors (PD) that can lead to a reduction in the sense of personhood for the person with dementia. These observations make it possible to see which individuals are faring well and which need additional support. (Brooker 1999)