Qualitative Experiences of Clients and Carers who have accessed the Extended Aged Care in the Home (EACH) packages in Rural NSW

Rural Research Capacity Building Project - June 2009

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Acknowledgements

- The clients and carers who consented to taking part in the project.
  Thank you for sharing your stories. You showed that the human spirit of caring is boundless.

- Thank you to Dr. Terry Joyce – my mentor.
  Research Academic, Discipline of Health. University of Newcastle NSW.
  Terry gave me much needed advice and encouragement throughout the project.

- Wendy Truer – my life long friend.
  You gave me objective, non medical insight throughout the compilation of this project. Thank you.

- Leonie Valuntas-Achilles
  Staff Development/ Library Assistant
  Grafton Base Hospital.
  Thank you for helping me to navigate the library and your ongoing support throughout the project.

- Staff and Educators of the NSW Institute of Rural Clinical Services and Teaching.
  Thanks to you, there were never any problems, just ways of finding solutions.

- Fellow researchers of the 2007 Research Capacity Building Project.
  The shared enthusiasm made this project so much more enjoyable.

- Management and colleagues from Grafton Community Health.
  Your support throughout the two years that has culminated in this paper has been greatly appreciated.

Participant's Quotes

"She knew more about strokes
than anybody had ever told me."

Alf's comment on his regular nursing review

"It makes me happier,
I just sort of feel that I,
we're sort of like kissing cousins."

Betty's comment on the support workers

"I wouldn't be able to have him at home because
he had to be lifted everywhere on a machine"

Comment from Charlie's carer on the equipment supplied with the EACH package

"Most people want to be able to stay in their own
homes as long as they can and I think this is
the ideal package to allow people to do that."

Comments from Dan's carer on EACH packages

Abstract

The purpose of this study was to gain an understanding of the qualitative experiences of both clients and carers who had accessed an Extended Aged Care in the Home (EACH) package in a small township on the far North Coast of NSW. The study was funded by the NSW Institute of Rural Clinical Services and Teaching.

EACH packages are relatively new and were established to provide flexible high level (nursing home) care to people living in their own homes. The evaluation of the pilot EACH packages trialled in South Australia and Western Australia in the mid to late 90s proved to be an outstanding success. This report acknowledged that there are few aged care services world wide that are comparable to the Australian EACH programme.

The number of EACH packages Australia wide grew from 288 in 2002 to 2,999 by June 2007.

The study involved semi-structured interviews of clients and carers receiving an EACH package in the selected township. Prior to interview, approval was sort and gained from the Ethics Committee of the North Coast Area Health Service.

The interviews were recorded and transcripts analysed to identify common themes or concepts based on a phenomenological process of the participant's lived experiences.

Following analysis, the findings were that all the clients and carers were overwhelmingly satisfied with EACH package in place. Key points concerning the satisfaction with the EACH packages were the focus on client care, one to one care, flexibility of care, service affordability and the availability of in house respite for carers.

With no research papers coming to light regarding EACH packages for clients and carers during the writing of this paper and the lack of comparative overseas services, the author recommends further qualitative research be undertaken.

Acronyms

ABS……Australian Bureau of Statistics
ACAT…….Aged Care Assessment Team
AIHW…….Australian Institute of Health and Welfare
CACP…….Community Aged Care Packages
CCCS…….Clarence Council Community Services
DVA……...Department of Veteran's Affairs
EACH…….Extended Aged Care in the Home
EACH -D…Extended Aged Care in the Home - Dementia
HACC…….Home and Community Care
NCAHS……North Coast Area Health Service

Executive Summary

Background
EACH packages offer high level care for older frail Australians wishing to stay in their own homes instead going into permanent placement. The packages are relatively new, growing from 288 in 2002 to 2,999 in 2007.

The author's anecdotal observations as a clinical supervisor of EACH package for four years were positive. Overall, the author found that carer's became less stressed and the one being cared for generally improved in overall health.

This Rural Research Capacity Building Project allowed the author to delve more deeply into the qualitative experiences of clients and carers on EACH packages.

Research Goals
During the two year compilation of this report, no research literature had come to light on EACH packages. Furthermore, the literature has shown that few services world wide compare to that of the Australian EACH programme.

The goal of this report was to shed some light on the qualitative experiences of client's and carers who had an EACH package in place.

Research Methods
Approval was obtained from the NCAHS Ethics Committee prior to contacting any potential participants. The following are key points regarding methodology used in this study:-

- Households that agreed to take part in the study signed a written consent prior to any work being undertaken.
- All households invited to participate in the study agreed to take part.
- The participants were out of the geographical area in which the author worked and were not known to the author.
- Data was collected by semi structured, face to face interviews that were digitally recorded and later transcribed.
- Themes and recurrent patterns were identified from interview transcriptions and were highlighted if they offered a unique contribution during analysis.

Findings

The interviews encouraged the participants to relate their experiences of the initial reception of an EACH package, the complexity of care received and how the EACH package has impacted on their lives. The clients and carers offered a range of experiences, responses and emotions.

Recurrent themes from the four households included:

- Eased burden of care for the carer with the EACH package in place
- Acknowledgement of the many tasks that the support workers attend while in the home
- Support, friendship and care offered to the client by the support workers
- Supply of goods and equipment for the management of complex care in the home
- Availability of regular in house respite
- Regular nursing review and clinical nursing as required

To summarise the findings from the themes:-

- All participants expressed appreciation with having help with hygiene and domestic duties. By having the physical burden of care reduces then the levels of stress reduced.
- All participants acknowledged excellent, flexible care they received.
- The theme of support and friendship with support workers ran very strongly, to that of kinship. Two participants used the terms, "*kissing cousins*" and, "*treat me like a brother"* to describe the bond with support workers.
- The supply of equipment such as electric lifters, wheelchairs and incontinence pads was a financial ease for carers.
- Regular in house respite enabled the carers to maintain an active social life and to continue with the caring role.
- Regular nursing review allowed health issues to be managed efficiently and quickly.

Conclusions and Implications

Without question the EACH packages have made the difference in allowing the four case studies to remain in their own homes. The research findings were overwhelmingly positive with all participants expressing satisfaction with the EACH package in place. Also the positive anecdotal observations the author had made with extensive EACH experience as a nurse supervisor were validated.

None of the participants could find fault in the service provided or offer any suggestions for its improvement.

The following points need to be considered regarding EACH packages:-

- EACH packages offer highly flexible high needs care at the point of need.
- Unlike nursing homes, there is no outlay or up keep in bricks and mortar.
- Equipment, expensive at initial outlay, can be reused.
- Staffing is flexible and not reliant on 24 hour a day rostering

In conclusion, more research need to be done on the overall use of EACH packages, the anecdotal evidence points to a flexible model of care that can adjust to our ageing community. The use of EACH packages needs to continue and funding acquired roll out more Packages across the nation.

Introduction

This report is the culmination of a two year research project funded by the NSW Institute of Rural Clinical Services and Teaching. The driving force to explore the qualitative experiences of clients and carers who accessed an EACH package came about from the author's four year experience of clinically supervising over 30 EACH clients in their homes. The majority of these clients had resident carers, some lived alone. Their places of residence ranged from older style houses in town, to modern townhouses, to isolated rural farm houses.

During this time the author worked closely with the Clarence Council Community Services (CCCS) responsible for the ongoing daily care for these clients. A relationship developed that provided holistic, client focused care designed to meet the needs of the clients and their carers.

An example of this client focused care involved a 90 year old retired farmer who lived with his elderly sister on the family farm. Both had never married. With a history of claustrophobia, he slept on an open verandah summer and winter. A tarp was strung up over him during inclement weather. Wary of services at first, this man came to accept showering and looked forward to the support workers visits. His sister enjoyed the new company but only relinquished a small role of the domestic duties. On one occasion he accepted a social drive in a car, a huge step considering his claustrophobia. One of the author's roles was to change a urinary catheter on a monthly basis. It was not uncommon to change the catheter on the verandah with a hen or two sitting on the verandah railing watching with great intent.

This anecdote speaks volumes about the enhanced quality of life that the recipients enjoyed because of the flexibility and level of care the EACH package provides.

The opportunity to do a qualitative research project on this cohort was one that could not be missed. If the author's previous observations of the success of the EACH packages could be validated by studying another cohort of EACH clients then the overall concept of high level care in the community could be considered successful and worthy of research on a larger scale.

Ageing and the Australian Population

The Australian community is an ageing community and a changing community. Increasingly, the ageing population relies on government services and Not for Profit organisations to provide a spectrum of specialist services to meet their varied needs. The ageing and potentially greater frailty of Australia's population is expected to continue. During 2007 the percentage of the Australian population aged 65 years and over was 13%. This figure has been projected to increase to between 23% and 25% by 2056 (Australian Bureau of Statistics, 2008). Of this population, one third lives outside major urban areas (Davis and Bartlett, 2008).

Frailty has been defined as "a condition in individuals lacking strength who are delicately constituted or fragile" (Yeow, 2002). Yeow continues that frailty can put a person at risk of adverse outcomes, vulnerable to environmental challenges and with impaired responses to stress. Frailty can lead to diminished ability to manage activities of daily living and diminished socialisation.

Older people, being either frail or well, make choices about where they live and the degree of support they require in order to optimise their health and well-being. They make these

choices with the help and advice of aged care organisations, health professionals, community and consumer advisers, and family and significant others. Healthy ageing is a balance between independent living and social support. The physical and emotional health of the elderly, linked with adequate financial and healthcare resources, help make the elderly feel safe and comfortable within the community (McMurray, 1999).

To meet the needs of our ageing population, the Commonwealth Government made policy changes to the *Commonwealth Aged Care Act* in 1997. The 'ageing in place' (Australian Institute of Health and Welfare, 2007) concept was one of these changes. The ageing in place concept brought two distinct areas of change.

The first area of change with ageing in place was to enable older Australians to move from partial dependence living to dependence living without having to change address. This allowed residents in low care facilities to age "in place" instead of having to relocate to high care facilities if their long term health deteriorated.

The second area of change for ageing in place focussed on diverting healthcare delivery to the homes of older Australians. With growing numbers of ageing Australians preferring to live in their homes instead of going to residential care (Australian Institute of Health and Welfare 2008), the concept of ageing in place was to keep older Australians in their own homes longer. The EACH concept of community based care instead of high level residential care is a direct response to the "ageing in place" concept.

It is the experiences of frail, older Australians living in a rural setting and have accepted an EACH package that will be the topic of this paper.

Community Based Aged Care in Australia: The Last 25 Years

During 1984, the Federal and State Governments jointly created the Home and Community Care (HACC) programme to respond to the needs of frail older Australians who wished to remain in their homes. One branch of this programme, Home Care, continues to provide a range of services such as domestic assistance, personal care and respite for both the frail elderly as well as younger Australians living with a disability. HACC services focus on a client base that was deemed to be "medically stable". The HACC funded Community Nursing service set up in 1984 for older frail Australians offers services such as personal care, wound care and palliative care. This service was the point of referral for medically unstable older Australians and those with an unstable disability. The nursing service offered was time limited and could not meet the needs of clients with complex needs requiring many hours of care per day. Therefore frail Australians with unstable, and often multiple, medical conditions often slipped through the government safety net.

Australians with top level private health insurance were, and still are, entitled to private home based care. One current major private health fund currently offers $400 per annum towards private home nursing care. This would allow short term nursing care but has not afforded ongoing management of the frail and elderly in the home.

Australians who have seen active service during periods of conflict are eligible for ongoing community based care through the Department of Veteran's Affairs (DVA). Encompassing all facets of care, DVA continues to allow veterans to be managed in the community by its brokerage to government and non government nursing organisations.

Other services have been set up for the frail in the community include Meals on Wheels and "Telecross". The latter, run by volunteers, was geared for the frail living alone and at greater risk of falls. At a set time each day a volunteer would phone the client who was registered on their books. If the phone was not answered then steps were in place for the client to be visited to make sure that they were safe.

During 1992 the federally funded Government Community Aged Care Packages (CACP) were initiated as an alternative to low level residential aged (hostel) care. Tailored to assist frail or disabled older Australians to remain in their homes, the CACP required an Aged Care Assessment Team (ACAT) assessment for access the programme. These packages were also available for residents of retirement villages, services included:-

- Personal care
- Social support
- Transport to appointments
- Home help
- Meal preparation

The CACP programme grew rapidly across the nation from 235 packages in 1992 to 35,383 packages as of June 2006 (Older Australia at a Glance, 2007).

The Extended Aged Care in the Home (EACH) programme commenced as a pilot in South Australia in 1993 and Western Australia in 1997. The pilot programmes were established to test the feasibility and cost effectiveness of providing high level (nursing home) flexible care to frail Australians with complex needs living in their own homes. Initially, an ACAT assessment is required for clients to be accepted for an EACH package. The EACH packages include qualified nursing supervision due to the high level of complex care required. As well as services that may be provided by CACP packages, an EACH package may include:-

- Assessment and management of pain
- Care and maintenance of tubes, enteral feeding and naso-gastric tubes
- Establishment, review and maintenance of urinary catheter care
- Maintenance of stomas and complex wound management
- Tracheotomy care and suctioning of airways
- Oxygen therapy including the provision of oxygen and equipment
- Provision of continence aids on an ongoing basis
- Carer respite which may include support staff staying overnight with the client
- Supply of equipment such as wheelchairs, lifting devices and adjustable beds

The *Evaluation of the Extended Aged Care at Home (EACH) Pilot Program* (Commonwealth Department of Health and Ageing 2002) returned a favourable response to the EACH pilot programme. The Executive Summary stated, "The high care the EACH pilot program offers is at least equivalent to quality high level care in residential aged care homes. In most cases, it exceeded the expectations the team brought to the evaluation." (Commonwealth Department of Health and Ageing, p.1, 2002)

The May 2002 EACH Census (ibid. p.18, 2004) showed that 288 clients were receiving an EACH package. By June 2007 this number had increased to 2,999 clients Australia wide (ibid. p.57, 2008).

In addition to the roll out of the EACH packages, the Federal Government rolled out 4,000 EACH - Dementia (EACH-D) packages from 2006 onwards (Australian Institute of Health

and Welfare, p.86. 2008). These packages were tailored to help older Australians living with a diagnosis of dementia. The aims of the EACH-D packages are to manage behavioural and psychological symptoms associated with a diagnosis of dementia.

Aged Care in the Clarence Valley NSW

From 1984 onwards the Clarence Valley, on the North Coast of NSW, were provided community nursing services from two Community Health Centres, one at Grafton and the other at Maclean. At the same time HACC funded "Home Care" service commenced offering assistance with personal care to medically stable frail and aged and those living with a disability. Home Care also offered domestic assistance and limited in-house respite. Other services set up in the Valley included Meals on Wheels and Telecross.

Two private nursing services commenced business in the mid 1980's, their primary clientele being returned service men and women. More private nursing service were to establish over the coming years. Once again, their primary clientele were to be government contracted DVA clients.

In 1995 the Local Government funded Clarence Council Community Services (CCCS) was contracted to be the Not for Profit Organisation to supply the case management for EACH and EACD-D packages. Community nursing services of the North Coast Area Health Service (NCAHS) were brokered by the CCCS to supply clinical nursing supervision for clients receiving these EACH packages. Clinical supervision for EACH-D clients is provided by a registered nurse from the Clarence Valley's ACAT.

If a client is willing to receive an EACH package, a fee is negotiated with the client by the CCCS. Clients are assessed on their individual ability to pay and a reduced fee for service may be negotiated. The current maximum daily contribution is $6.78 or $94.92 per fortnight (Centrelink, Australian Federal Government. 2008).

A large proportion of clients who receive EACH packages have resident carers. Due to the clients' high level of needs, the carers are eligible to receive the Australian Government *Carer Allowance* (ibid.). The non means tested *Carer Allowance* currently stands at $100.60 a fortnight.

The Clarence Valley is currently funded for sixteen EACH packages. Twelve packages were designated for the upper Clarence Valley while four packages were designated for the lower, and coastal, Clarence Valley. Thirteen EACH-D packages are currently funded across the Clarence Valley.

Literature Review

In researching this paper, it is the author's finding that very little has been surveyed or written about the experience of older Australians receiving community based care. No papers have come to light regarding satisfaction, or experiences, of older Australians who have accessed an EACH package during the writing of this paper.

Tinker *et al* (2007) quoted in McLaughlin and Mills (2008) support the concept of older people wanting to stay in their own homes. Tinker *et al* state, *"that older people want to stay in their own homes with repairs and adaptations over time"*. This statement supports the two concepts of CACP and EACH packages. Adaptations can be viewed as being physical, such as home modifications which may be as simple as installing hand rails, to adapting a service such as CACP or an EACH package to meet an older person's needs.

Gardner, Browning and Kendig (2005) published a research paper on older Australians' options of living in retirement villages or staying in the community. Their paper stated that little research had been undertaken on, *"the importance of housing for the health and well-being of older people"*. On a broader note, Eagar et al (2008) stated that the amount of evidence concerning community based care in general is varied and limited.

Davis and Bartlett (2008) state that their extensive literature search from 1992 to 2007 produced little literature on aged care in Australia. The available literature which came to light mainly focused on urban and rural comparisons or small rural specific qualitative studies. Little research on older rural men in particular had come to light. No reference was made to older frail Australians who have been assessed for low or high care placement.

One research paper came to light regarding the use and satisfaction of CACP in Sydney. This paper, by Thomas, Woodhouse, Rees-Mackenzie and Jeon (2007), was a descriptive pilot study using both qualitative and quantitative methods of data colection. This study stated that their extensive electronic data base search revealed no research done on CACP satisfaction. However, their own findings painted a dim picture of client satisfaction with CACP. Their key findings were that the service lacked flexibility, quality and continuity of care. Communication often broke down between CACP services, the acute care sector and the client. This posed as a significant barrier to efficient CACP management. Participants of this study reported that they felt that support workers used the banner of Occupational Health and Safety as a means of not carrying out tasks within the home. Other issues raised were staff recruitment, retention and support.

The *Evaluation of the EACH Pilot Program (2002)* report prepared by Siggins Miller Consultants for The Commonwealth Department of Health and Ageing made the bold and broad statement that few services world wide compare to the Australian EACH programme. The evaluating team found the care at least equivalent to high level residential care and in some instances, the care exceeded the team's expectations. Their extensive search of electronic data bases yielded very little literature about extended high level aged care in the home.

Study Aims

The purpose of this study was to gain an understanding of the qualitative experiences of both clients and carers who had accessed an EACH package in a small township on the far North

Coast of NSW. With the author's experience with EACH packages as a clinical nurse supervisor followed by the fact that little literature has come to light on EACH packages; the aim of the project is to add to the body of knowledge concerning EACH packages in the community.

Methodology

Approval to commence the study on clients and carers who have accessed an EACH package was obtained from the NCAHS Ethics Committee prior to contacting any potential participants.

The author had not been involved with the care, or had contact, with the participants prior to the research project commencing. The participants were clinically managed by a registered nurse from an adjacent community health centre. The nurse approached the potential participants on the author's behalf. All four households approached to be part of the project agreed to meet with the author and discuss the project. All four households agreed to take part in the study and signed a written consent prior to any work being undertaken. Three of the four households that agreed to take part in the study had a resident carer and one participant lived alone.

Data was collected by semi structured; face to face interviews that were digitally recorded. This study was modelled on a phenomenological approach, the interviews being transcribed verbatim and studied to give a sense of the holistic nature of the participants' lives. Themes and recurrent patterns were identified from the transcriptions and were highlighted if they offered a unique contribution during analysis. Haynes and Watt (2008.p.46) state that phenomenological research is "directed towards the person's reality and examines the more subtle feelings" that they may encounter. The aim was to gather rich descriptions of the participants lived and shared experiences in the context of high level care while living in the community.

As the decision to accept an EACH package into the home was a joint decision by the client and the carer, the interviews were held with both client and carer present. The author's decision to interview the client and the carer together was queried by both educators during research workshops and by my mentor, Dr Terry Joyce. Discussions focused on the fact that richer data from the different perspectives of care giver and care provider would be gathered if these participants were interviewed separately.

The author maintained that the EACH packages in participating households were set up with the client and carer working together as a team. Both client and carer would need the common goal, driven by desire and commitment, to keep the client in the home. As the purpose of this study was to explore the experiences of this 'household team' then the interview would best be suited by having both present during interview.

During interview, two carers stated that the person being cared for had expressed concern about the interview and had expressed fears that the interview was somehow involved in placing them into permanent care. Their presence at interview had helped to allay these fears and gave an opportunity for them to share there experiences with the EACH package.

Case Studies

The four case study households currently receiving an EACH package are all resident at a small coastal town on the North Coast of NSW, Australia. The town is a popular holiday destination with a permanent population of 6,000 people. This population is estimated to double during peak holiday periods. There is a strong local history of commercial fishing with a large fishing fleet still active from the town's harbour. Sugar cane is the major crop grown immediately inland from the township and the town is also bounded by a large national park. There is a small district hospital of 42 beds in a township 20 kilometres away and the major regional city with a base hospital and a large private hospital is one and a half hours drive away.

"Alf" was a 93 year old male living alone. A cerebrovascular accident many years earlier had left him partially paralysed down one side and with a minor expressive speech impediment. His wife had died 12 months prior to this interview. He accepted an EACH package not long after his wife's death. Alf had a son who lived a few hours drive away; the son would stay periodically for a couple of weeks to assist his father.

"Betty" was in her 70's and lived with her carer husband. Betty had been diagnosed with Parkinson's disease and myasthenia gravis. The combination of illnesses made Betty completely chair fast with transferring from her chair or bed being done with the aid of a lifting device. Incontinence of both bowel and bladder was also a major concern. This couple had accepted an EACH package approximately 12 months prior to this interview.

"Charlie" was a 94 year old man lived with his carer niece. They had accepted an EACH package almost two years previous to this interview. Charlie had a history of major cardiovascular problems resulting in a below knee amputation. Charlie was also completely chair fast and dependant on a lifting device for transferring and he also had a permanent supra pubic urinary catheter due to a history of urinary incontinence.

"Dan" was in his 80's and lived with his carer wife. Dan had advanced Parkinson's disease, was aphasic and was also legally blind. Dan had been previously placed in permanent high level care for four months. His wife brought him back home on an EACH package as he was distressed and disorientated while in care. Dan had been on an EACH package for two and a half years prior to this interview.

Findings

The interviews encouraged the participants to relate their experiences of the initial reception of an EACH package, the complexity of care received and how the EACH package has impacted on their lives. The clients and carers offered a range of experiences, responses and emotions. Dan was aphasic and did not participate in the interview but was present at the time of interview.

Recurrent themes from the four households included:

- Eased burden of care for the carer with the EACH package in place
- Acknowledgement of the many tasks that the support workers attend while in the home
- Support, friendship and care offered to the client by the support workers
- Supply of goods and equipment for the management of complex care in the home
- Availability of regular in house respite
- Cost of the EACH package
- Regular nursing review and clinical nursing as required
- Issues with the distance to major hospitals for complex care
- Perception of the need for more EACH packages

Each of these themes will now be looked at in some detail.

Eased burden of care for the carer with the EACH package in place

The three households with carers expressed their appreciation for having the physical needs, such as hygiene and housework, attended to by the support workers. All three carers were advancing in years and had their own health issues to deal with. By having this physical burden reduced they found that their overall stress levels were reduced.

All four households have a local general practitioner that regularly made home visits and bulk billed under the Medicare scheme. This represented both a financial ease as well as reduction in stress with the knowledge that the doctor was available as required and would home visit.

Betty had been using a private nursing service prior to accepting an EACH package. The carer husband found the service "*didn't seem as caring as the people with the EACH programme*". He expanded by stating that "*they didn't arrive on time, you didn't know when they were coming*". The need for routine was important for this carer, along with the sense of trust in the care Betty was to receive.

Charlie had been using an EACH package for two years, the carer niece stated, "*I wouldn't be able to have him at home because he had to be lifted everywhere on the machine*". Prior to the EACH package they had been using a three day a week Home Care service. "*When he had his leg off it was getting harder for me to handle him because I had a bad leg and shoulder*". Charlie's niece implied that the Home Care service was good but more help was needed to help keep Charlie at home. Like all the other carers, she was advancing in years and had her own health issues; a shoulder reconstruction was planned sometime in the coming months. She stated that after the operation it would, "*probably be eight weeks before I can really do anything….so basically its two patients here*". She went to say that with the extra services they would cope, "*whatever I need they do for me as well*". In reference to the case co-ordinator of the Council Support Services, "*anything that you think you need or any*

problem you just ring the office and she's on it straight away, I don't think it could be improved anyway".

The carer of Dan had taken her husband from a high care facility as he was "*fretting and could not cope*" two and a half years prior to interview. The decision to have Dan placed in high residential care was influenced by the difficulty she experienced in showering him and his tiredness at night when it came to transferring him to bed. She had wanted to bring him home earlier but accepted this to be impracticable with his high care needs and the limited services available. She "*was sure that there was something coming to be of help to me and it was the EACH package*". The care received was summed up with, "*I think he feels he gets well looked after. Most people want to be able to stay in their own homes for as long as they can and I think this is the ideal package to allow people to do that. Why should they go into a home where they don't have individual care, its one to one care that counts*".

Acknowledgement of the many tasks that the support workers attend while in the home

All of the sample households acknowledged that the workers did excellent work in caring. It was clear that all the households appreciated the flexibility of the care they received. All households received domestic help. Three of the households received twice daily visits by support workers. One household had services in the mornings five days a week and seven days a week in the evenings.

Alf stated that the helpers visited daily to dress and to give him a shave. The workers returned in the evenings to help put him to bed. Alf requested that he be assisted with showering only once a week. This request reflects the holistic nature and client focus of an EACH package. In a regimented structure of care the concept of weekly showering may be frowned on and cause friction between carer and care receiver. When asked about the general care he received he stated, "*if anything wants doing, they do it, anything required, they're very, very good*". Alf happily stated, "*I'll get a pie for today, first time this week, treated like that*". Alf was a retired labourer from Western Queensland, for him, a meat pie was a first class meal.

Betty was showered and dressed five times a week with workers returning in the evening to put her to bed every night of the week. On weekend mornings the carer showered and dressed Betty. The carer husband, in an effort to assist the workers, "*bought lots of things like carpet cleaners and ironers and everything that gets advertised on television.…to sort of help the whole process*". The client backed her carer husband with the statement, "*the girls are really working very hard, they are just wonderful people*".

Charlie's carer stated that, "*nothing fazes them* (the workers), they'll say, "*do you want to stay in bed a bit longer today and I'll come back around half past twelve or something*". This is a significant example of the flexibility of a tailored EACH package which has been designed to meet the needs of the client.

Dan receives twice daily visits, seven days a week. Dan's carer acknowledged that her caring role is, "*still a big job, made a lot easier by having people come in and help*".

Support, friendship and care offered to the client by the support workers

The theme of support and care from the support workers ran strongly throughout all interviews. The support workers were guests in the participant's homes and an emphasis of working together and building trust was important for the EACH package to work successfully.

Alf was quite succinct in his views of the support workers. "*They do a good job, put it that way, very good job*". Contrary to Charlie, he enjoyed a set routine with the care workers and how the routine had benefited him, "*the helpers now are the best it's been, a bit of a pattern about it somewhere*". He summed up the care received with, "*I think they do everything required; they're good, very good*". When asked about going on outings with the support workers he replied, "*I'm 93 as you know; I've done enough touring around*".

Betty stated, "*I feel that I get a lot of comfort and help from the people that come in*". Betty went on to say, "*I find them absolutely fantastic, they come in and we have lunch together. It makes my life happier, I just sort of feel that I, we're sort of like kissing cousins*". The term of kissing cousins implies that a very strong bond of friendship, of family, had developed between the client and the support workers.

This theme of family bonding was also reflected by Charlie, "*the carers are very good; they treat me as a brother, it's wonderful*". Charlie, a retired commercial fisherman, had accepted only one outing with the support care workers. The outing was to a nearby lake he used to fish, "*ah, bring back old fishing memories, the girls arranged that for me and that happened and now I am satisfied*". Charlie's carer niece supported the rapport that he had with the support workers, "*the laughter sometimes is just unreal*".

Supply of goods and equipment for the management of complex care in the home

Part of the EACH package is the supply of goods, such as incontinence pads, catheters, lifting devices, shower chairs and height adjustable beds. The cost of these items prior to accepting an EACH package was a major concern for some of the participants.

The CCCS is obligated to look after the wellbeing of its employees. Three of the participating households were supplied with lifting devices by the CCCS to manage the risk of manual handling injury when transferring the client while in the home.

A major concern for Betty was the faecal incontinence. Her carer stated, "*we have quite a few accidents we cannot control, she cannot control. I get a bit mad, we have our arguments, we get fixed up again. The provision of those toiletries* (incontinence pads) *was very important. It sort of enables us to work well with the programme*". Lack of mobility and the inability to transfer from a chair presented as another major stressor. The provision of an electric lifting device was used by the carer and support workers. Betty was not keen on the device as it was slower than manually lifting her; however she accepted it resolutely by saying, "*it's better than being dropped on the floor*". Which may be the case in a manual lift and a worker injured themselves during that lift. Betty was looking after the wellbeing of the support workers.

Charlie's leg amputation made him totally dependent on the lifting device; he could not weight bear at all. His carer niece stated that without the lifter supplied by the EACH package, "*he would be in a nursing home*". The cost of catheters for Charlie was also a major concern prior to the EACH package commencing, Charlie's carer stated, "*when you buy a box of 12 and it's a something and a hundred dollars, it's a lot out of a pension*". Catheters require changing monthly by a registered nurse.

Dan's carer could not have taken him out of the nursing home without a lifter being supplied. She also had a different view on the lifting device provided. Dan had a history of falls and she had to call an ambulance to pick him up prior to being supplied with a lifter. "*I didn't like calling them* (the ambulance*) because I felt that they could have been needed for a serious*

accident". The town with the nearest ambulance station is a 20 minute drive away. Other equipment supplied for Dan were hand rails in the bathroom, a shower chair and incontinence pads for night time use.

Availability of regular in house respite

When phoning the households to make an appointment for interview all of the carers clearly stated that the respite day was unavailable. This time was closely guarded as their time away from the caring role.

The carer for Betty was a keen golfer and enjoyed two afternoons a week to play golf with his friends. He was on the executive committee for the golf club and maintained a respectable golfing handicap. During the interview the topic of a recent 'hole in one' brought animated banter between the carer and his partner. On some respite days, Betty went out with a support worker for lunch. Betty's carer stated he was, "*fitter now than I was three years ago*". He added, "*I'm learning to cook better……..we eat better……....eating fresh things all the time…..…don't have as many left over things in the fridge*." He attributed his improved fitness to his continuing ability to keep Betty at home.

Charlie's carer took Wednesday afternoons off for respite; this time was used for shopping or generally getting out of the house. The nearest major shopping centre was an hour drive away.

Dan's carer played tennis one afternoon per week and cards on another. She also attended a local Parkinson's disease support group on a monthly basis. Attending the Parkinson's disease support group gave her the opportunity to share stories with other carers concerning the management of Parkinson's disease.

It was clear on interview that respite time was well utilised and highly prized. This was the carer's own time to step out of the caring role.

Cost of the EACH package

Carers commented that the EACH package was not a financial burden and was offset by the *Carer Allowance*. The supply of expensive equipment was also a major cost savings. The ongoing supply of incontinent pads and catheters was also acknowledged as a huge cost savings. All of the participants in the study were on a pension.

Alf did not have a carer, concerning the EACH package he stated, *"I can afford it…..I get a full pension"*.

Betty's carer stated, "*we pay $164 a month to the Council and we get about $200 back from Centrelink so it's a pretty well break even sort of situation"*. He had also bought different cleaning aids for use by the support workers, "*to sort of help the whole process"*.

Dan's carer also stated that the *Carer Allowance* was a financial help and that the EACH package was well worth its value.

Regular nursing review and clinical nursing as required

All of the clients received clinical nursing review by a registered nurse on a monthly basis. All the households have a "communication book' for visiting support workers to make relevant daily comments regarding ongoing care. This book is reviewed by the visiting registered nurse. If a nursing need arises, such as a skin tear, the support workers contact the

CCCS co-ordinator who contacts the community nurse. Following a home visit and assessment the nurse instigates the necessary care as required. The clinical supervising nurse and the case co-ordinators liaise regularly so as to maintain focused, quality care.

Alf expressed confidence in this review, "(she) *knew more about strokes anybody had ever told me*". Alf had experience in nursing home respite care. His wife had often travelled and he went into care, his comments about the care received were, "*he's had a stroke, wipe him off…..I wanted bloody help*".

Due to Charlie's immobility and poor cardiovascular condition, he was prone to pressure areas or skin tears. The carer stated that if she phoned in regard to a nursing need, "*they will come, they're there in a flash, it's all very good actually*".

Dan was also immobile and prone to pressure areas. His carer stated that, "*all the community nurses that come are all very good*".

Issues with the distance to major hospitals for complex care

The township has no hospital or ambulance service. The nearest ambulance station and 42 bed hospital is 20 km away. The largest regional hospital, Lismore Base Hospital is an hour and a half drive away and a large private hospital; St Vincent's Hospital is also located in Lismore.

Betty came onto the EACH programme after she had fallen and broken her femur. The initial injury occurred at 9am and involved two ambulances to three hospitals until she was finally admitted at 11pm that night to a major private hospital. Following surgery she was transferred back to the nearby base hospital and after a few weeks, back to the local district hospital. Unfortunately, while in this hospital, she fell and broke the other femur. Another leapfrog by road ambulance occurred. Firstly, to Lismore Base Hospital and then on to St. Vincent Private Hospital for final admission. Following further surgery Betty was transferred back to the small regional hospital for rehabilitation, all up Betty had spent 65 days in the hospital. Her carer husband was concerned about her mental wellbeing. "*Once you've been in hospital for 65 days you start conversing with the fairies*". He brought her home with minimal training with equipment and straight onto an EACH package.

Charlie had a similar experience of leapfrogging the same three hospitals by ambulance following a myocardial infarction. His carer niece was concerned that he had gone by ambulance from the house early in the morning she did not get to see him until 4pm in the afternoon. This length of time was due time on the road between the hospitals and the time spent in the first two hospital outpatient departments prior to Charlie being finally admitted to the third hospital.

The general feeling conveyed both households was of resignation with the hospital leapfrog process following their respective acute medical incidents.

Perception of the need for more EACH packages

All of the households expressed satisfaction with the EACH packages. All implied that more packages would be of benefit to the frail and ageing population who wanted to stay in their own homes. When the interviews had finished, and the author was casually winding down with the participants, two carers mentioned that they hoped that this project would lead to more EACH packages. An interpretation of this statement could be that the participant's answers were skewed towards social desirability to gain more packages. However, the author

feels that the overwhelmingly positive comments about the EACH packages from all the participants makes this unlikely.

Charlie's carer expressed her view's on the need for more packages by stating, "*I'm amazed that there are only five EACH packages in this area. There are so many people that do need help……more people should have the chance of having the service in their own home*".

Dan's carer summed up by saying, "*most people want to stay in there own homes for as long as they can and I think this is the ideal package*".

Discussion

This paper adds considerable insight to an area were little literature is available. The only paper to shed any light on EACH packages were the positive comments from the *Evaluation of the EACH Pilot Program (2002).* The author was surprised at the lack of literature concerning EACH packages. The Federal Government has shown it's faith in the EACH package model of care by its increased funding of 288 Packages in 2002 to 2,999 Packages in June 2007. This represents a substantial outlay of funding with little evidence to support this move towards community based care.

Unlike the dim findings of the paper by Thomas *et al* (2007) on satisfaction of CACP in Sydney, the participants in this study all clearly stated that the care they received was flexible and of high quality. No issues concerning communication with care co-ordinators was raised throughout the interviews. No issues concerning the support workers were raised by the participants. The vast difference in the findings from Thomas *et al* (2007) concerning CACP and the author's findings are open to debate. The author's experience of working predominantly in the rural sector as a community nurse has shown that services generally have good lines of communication and the overall workforce is stable. This may not be the case in large metropolitan areas with multiple services overlapping which can offer a greater opportunity for lapses in service.

The CCCS have a stable and well trained workforce with an emphasis on staff support and ongoing education. This presented throughout the interviews by the strong bonds of friendship expressed by the participants as well as a dependency for the care received. These bonds can only be grown through ongoing trust and a strong degree of continuity of care.

Haynes and Watt (2008.p.46) state that phenomenological research is "directed towards the person's reality and examines the more subtle feelings" that they may encounter. All the participants strongly expressed the opinion that the service was invaluable to them. There was no subtly in the participant's comments regarding the EACH packages. The overarching phenomena for the clients and carers in this study were the strong sense of dependency and trust that had developed with the EACH packages. Without the packages, permanent placement was the only option open to them. For the one participant who lived alone, the package helped him to maintain his independence, this man had previous experience with high care placement and strongly verbalised his desire to stay at home.

One of the main weaknesses in this study is the small number of participants, four participating households represents a very small portion of the national number of EACH packages. Also these four households are case managed by the same Not for Profit Local Government organisation. A more robust phenomenological study would have more

participants and have participants managed by different organisations across different geographic areas. This would give a better and broader insight to the phenomenological experiences of Australians who have accessed an EACH package.

The Federal Government appears to be committed to funding and expanding EACH packages. This would appear to be a direct result of our ageing population and the need for quality aged care. In the following years the EACH packages will most probably continue to grow, with more Australians choosing to remain in their own homes as they grow older. The EACH concept of care has advantages over traditional high level care institutions, unlike these institutions, EACH packages offer:-

- Highly flexible, high needs care at the point of need
- No outlay or up keep in bricks and mortar
- Flexible staffing and no reliance on a rigid 24 hour rostering system
- Transportable packages to meet the changing demographics of an ageing population

In conclusion, more research need to be done on the overall use of EACH packages, the anecdotal evidence points to a flexible model of care that can adjust to our ageing community.

The use of EACH packages needs to continue and funding acquired roll out more Packages across the nation.

Conclusions and Recommendations

This qualitative research paper explored the experiences of four households receiving an EACH package. The research findings were overwhelmingly positive with all participants expressing satisfaction with the EACH package in place. Also the positive anecdotal observations the author had made with extensive EACH experience as a nurse supervisor were validated.

This serves as a credit to the CCCS case managers and the support workers, as well the supervising nurse and community nurses from the NCAHS involved in clinical care. The lines of communication between all organisations involved in the ongoing care of these EACH clients have been shown to be well forged and maintained. This is an indicator of a combined focus on quality client care.

Without question the EACH packages have made the difference in allowing the four case studies to remain in there own homes. The key points about the packages highlighted in the responses from the participants include the following:-

- Client focus of services
- One to one care
- Flexible provision of care
- Affordability of care
- Availability of respite

Based on the importance of these packages and their adaptability, the author would recommend their more extensive use.

Due to the limited research on EACH packages, the author recommends further research involving:-

- Individual interviews with carers and care receivers so as to gain a deeper insight to the individual experiences with EACH packages in the home
- Larger numbers of participants in studies
- Research in different demographic and geographic regions where EACH packages are in place

References

Australian Bureau of Statistics (2008), *Population Projections, Australia,* Cat. No. 21013222.0
ABS, Canberra.
http://www.abs.gov.au/ausstats/abs@.nsf/mf/3222.0 Accessed 20.01.2009

Australian Government. (2008) Centrelink, *Who can get the Carer Allowance (caring for an adult 16 years or older).*
http://www.centrelink.gov.au/internet/internet.nsf/payments/qual_how_caadult.htm.
Accessed 12.11.2008

Australian Institute of Health and Welfare (2008). *Aged care packages in the community 2006-07: a statistical over view.* Aged care statistics series no. 27. Cat. No. AGE 57. Canberra AIHW.

Australian Institute of Health and Welfare (2004). *Extended Aged Care in the Home (EACH) Census: A report on the census conducted in May 2002.* AIHW cat. No. AGE 33 (Aged Care Statistics Series No. 15). Canberra: AIHW

Australian Institute of Health and Welfare (2007). *Older Australians at a Glance: 4th Edition.* Cat. No. AGE 52. Canberra AIHW.

Davis S, Bartlett H. (2008*) Healthy Ageing in Rural Australia: Issues and Challenges.* Australasian Journal on Ageing, Vol 27 No.2 June 2008, 56-60 p.56

Department of Health and Ageing. (2008) *Extended Aged Care at Home Packages.* Canberra: AIHW http://www.health.gov.au/internet/main/Publishing.nsf/Content/ageing-commcare-each.htm. Accessed 12.11.08

Eagar K, Owen A, Cranny C, Thompson C, Samsa P. (2008) *Community Health at the Crossroads: Which Way Now?* Final Report of the NSW Community Health Review. Centre for Health Service Development, University of Wollongong, NSW.

Gardner I, Browning C, Kendig H. (2005) Accommodation options in later life: retirement village or community living? *Australasian Journal on Ageing.* Volume 24 No 4: p.188-195

Gibson D, Rowland F, Braun P & Angus P (2002). *Ageing in place: Before an after the 1997 aged care reforms.* AIHW Cat. No. AUS 26. Canberra: AIHW.

Haynes DF, Watt P. (2008). The lived experience of healthy behaviours in people with debilitating illness. *Holistic Nursing Practice.* 2008 January/ February; 22(1) :p44-45

McLaughlin T, Mills A. (2008) Where will we live when we get older? *Quality in Ageing.* Volume 9 Issue 3: p15-21

McMurray A. (1999) Community Health and Wellness: A Sociological Approach. Mosby, Sydney.

Thomas M, Woodhouse B, Rees-Mackenzie J, Jeon, Y. (2007) Use of and satisfaction with Community Aged care packages in the eastern suburbs of Sydney. *Australasian Journal of Ageing.* Volume 26 (1), March 2007, p 8 -24

Smiggins Miller Consultants (2001). A report for the Commonwealth Department of Health and Ageing. *Evaluation of the Extended Aged Care at Home (EACH) Pilot Program.* March 2001 – No.40

Yeow T B. Successful Aging. (2002) *The Singapore Family Physician.* Oct-Dec 2002; Vol 28(4) p107-112.