An evaluation of which respite options work best for people with dementia and their carers living in rural New South Wales

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Introduction

Involving people with dementia (PWD) and their carers in all aspects of research is increasingly recognised as essential to inform services and care. Supporting participation in research will overcome much of the stigma associated with dementia and also reflect the value of PWD within society.

Dementia, recently designated as Australia’s ninth National Health Priority Area is the greatest single contributor to burden of disease due to disability as well as the second greatest single contributor to the cost of care in residential aged care after incontinence.

The majority of people with dementia prefer to live in their own homes for as long as possible. This is possible with support of family and community care assisting with communication, cognition and emotion, as well as mobility, self-care and other activities of daily living. The increasing workload and associated stress of the family caring role is correlated with poor health outcomes and earlier institutionalisation.

Recent studies and consultation with carers identified limited capacity of health and community care services to provide respite programs that are responsive to needs and preferences. Difficulties included: geographic variability impacting access to services, lack of information, cost and cultural impediments, navigating the service system, service flexibility plus poor experiences for PWD in hospitals, multipurpose services and residential care facilities.

Respite services provide a wide range of benefits to caregivers, including increased general health and vitality, reduced perception of burden, increased social support, lower levels of depression and delayed institutionalisation. Only 30% of carers report using a respite service where a referral has been made and services are readily accessible. Carers report general dissatisfaction with traditional planned programs and most respite care being unhelpful in terms of acknowledging interests and diversity of PWD.

Innovative person-centred services that focus on the individual’s quality of life and wellbeing, are less well dispersed, limiting choice for many PWD and their carers.

Activities and breaks for couples rather than the traditional focus on separating the PWD and carer, are one example. Similarly, creative activities such as music, art and dance that promote use and the ‘language of the unconscious’, are also person centred in their approach.

A gap in knowledge exists regarding community based programs within a rural context. The Australian Government’s recent Aged Care Reform Package has acknowledged the over regulation of aged care programs and that current policy and program funding are not person centred. Greater Hume Aged and Community Services (GHACS) have been moving from more traditional programs to innovative person and carer centred respite programs however, current policy and funding continues to be a barrier to sustaining their efforts. There is a need for more research to ascertain the most effective interventions for carers at specific stages of their caring journey, specifically in a rural area.

This study aimed to evaluate the quality of life outcomes and effectiveness of respite services to PWD and carers in the Albury, Corowa and Greater Hume Shires in New South Wales.
Methods

Theoretical propositions were drawn from Bamford's person-centred components and were adapted to an Australian rural community providing a framework for ordering and analysing the data. Field testing indicated that Bamford's methods were acceptable and had good face validity. The tools were applied to all stakeholders, reflecting the view that the principles and components of person-centred care are equally relevant to PWD, carers and staff. Questions relating to staff satisfaction and organisational culture were excluded as these were not within the scope of the study.

The areas of Albury, Corowa and Greater Hume Shires are geographically dispersed with a total population of 68,623 people living across the catchment of 8,500 sq km. Of the total population, 16,000 are >65 years (23%). Recent statistics indicate the prevalence of dementia in the Albury State Electorate to be 1,047 people. By 2020, this is projected to increase significantly to 1,420 people.

The activities evaluated included a singing, art and coffee break social support group. The lead researcher for this study was unknown to the organisation, participants and activities. Ethics approval was obtained from the Albury-Wodonga Human Research Ethics Committee.

Participants with dementia were recruited based on the individual being known to their carer or direct care worker/s as having the capacity to consent. To facilitate recall and help in articulating their views, interviews were conducted with PWD in the activity setting.

Overall 65% (13/20) of the target group (PWD) were perceived to have the capacity and capability to consent. PWD had a great desire to tell their story and their participation was supported by staff and/or carer (Table 1). Structured conversational interviews were carried out with these thirteen participants.

<table>
<thead>
<tr>
<th>Group</th>
<th>Participants</th>
<th>Respondents</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albury’s Got Talent (Singing)</td>
<td>10</td>
<td>5</td>
<td>50%</td>
</tr>
<tr>
<td>Art from the Heart</td>
<td>3</td>
<td>2</td>
<td>66%</td>
</tr>
<tr>
<td>Coffee Break</td>
<td>14</td>
<td>6</td>
<td>42%</td>
</tr>
<tr>
<td>Study Target</td>
<td>20</td>
<td>13</td>
<td>65%</td>
</tr>
<tr>
<td>(Perceived capacity and capability for consent)</td>
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Carers were very keen to participate in either focus groups or paper based surveys and recruitment exceeded the target number of twenty (Table 2). Staff invited included managers, case managers, direct care workers and activity facilitators and 13 staff responded by completing either a paper based or online survey consisting of items on a 1-5 always to never scale (Table 2).

<table>
<thead>
<tr>
<th>Group</th>
<th>Target</th>
<th>Respondents</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td>Carers</td>
<td>20</td>
<td>22</td>
<td>110%</td>
</tr>
<tr>
<td>Staff</td>
<td>15</td>
<td>13</td>
<td>86%</td>
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</tbody>
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Data analysis

Data was analysed using interpretivism logic and thematic analysis. The design was chosen because it is based on social reality and the lived experience and interpretation of the persons’ sense making of their respite experiences. Theoretical propositions, based on Bamford’s person-centred components for respite care, were used as a framework to evaluate the attributes of the respite programs. The framework has nine components of person centred care and findings are presented for each of these.
Findings

Respecting individuality and values

Persons with dementia

Participants felt like unique individuals who were valued and recognised for their likes and dislikes. They appreciated being greeted by name and treated as an individual and felt there was plenty of time for them to enjoy their activity. “We are never rushed, if you cannot get the work (Art) done in time, they help you”. Participants enjoyed staff joining in the various activities and felt they cared and were interested in their lives. “We are a family” was how one respondent summarised his view, with another valuing the hug and welcome for the New Year, “it was nice”.

Carers

Carers felt respected, “they know what we are going through” was how a carer described the staff. Another carer commented, “they recognise our needs and preferences, if we do not think a program is suitable, then we do not continue and that is accepted”. Carers very much appreciated the atmosphere of the Coffee Break, “the staff member is wonderful, she introduces us and knows us and knows what we are going through”.

Staff

Over 92% of staff felt that the activities respected the individuality, diversity and values of the client however 7.7% thought that this was only the case sometimes. Staff requested their preference for having more information around the individuals likes and dislikes as well as carer feedback, recommending “regular consultation regarding the impact of the respite service, ie, is it making a difference to the carer as well as the PWD?”

Enhancing psychological well-being

Persons with dementia

Looking forward to going to the activity and enjoyment were two of the most common responses. Responses included “I tell rude jokes, we have a good laugh, that is the best part,” and “I enjoy it a lot, it gets me out of the house”, one described the laughter and said “it is the best medicine you know.” Others commented on the memories, with some sadness in their voice. “They are old songs, I know most of them, they are true songs, they bring back memories, I like the songs” One respondent summed up her feelings for Singing. “From Tuesday to Thursday I am happy, I wake up on Thursday and I am very happy because I am going to singing, I go home and I am happy, I sing all day, sometimes it brings a tear to my eye because it reminds of when my husband went away to war and I missed him.” The only male in the group described how he was unable to sing anywhere else, ‘if I sang in my unit, the neighbours would wonder what was going on”, I can sing here as loud as I want to, I enjoy singing and have done since I was 5 years old.”

Similarly, Art was also highlighted as promoting strong positive emotions. “I just love it, I would not miss it” and “I never worry about coming, I worry about getting here, I like it here a lot”

Staff were acknowledged as the reason for the positive atmosphere. “They are very skilled staff and enthusiastic participants” and “very special people.”

Carers

Over 80% of carers reported the good mood their relative was in after the activity. “If he is happy, then I am happy”, and “we love it, we feel happy when we go, we want to go, we have very good reasons if we cannot go.” One carer expressed the activity as making her partner “happy for the day”.
Staff
Over 90% of staff felt that the programs enhanced psychological wellbeing recognising the importance of happiness and contentment in the context of challenging health and social circumstances. Comments included: ‘making a person feel safe and loved in a non-threatening environment’, another staff member “aimed to provide a caring, social and enjoyable activity’.

Promoting autonomy

Persons with dementia
Clients welcomed choice. Responses included “if we do not want to join in, it does not matter” and, “we could go outside if we want to”, or “sit back and listen” or “just watch”. However some PWD preferred more choice in the Art and Singing programs.

Carers
Overall carers were happy with choices where they could participate as a couple, they loved the coffee, tea and snacks and felt very well looked after. Over 80% of carers did not feel they had the need to get more involved in making decisions about the respite program.

Staff
Over 60% of staff felt the program usually provided choice and that clients could have input and control over their activities. Concern was raised over the restrictions in Art and to some extent Singing. Some staff felt as though others were indulging in their own interests rather than the client’s interest.

Promoting a sense of responsibility

Persons with dementia
Overall PWD felt a sense of responsibility to go and enjoy the activity, although not attending was a choice they felt they had.

Carers
Over 83% of carers neither agreed or disagreed with the need to be more involved in making decisions about respite care. The remaining carers were divided between wanting some more involvement and no involvement in decisions. Carers welcomed the control they had around attending coffee group, “if I did not want to go and felt it was not worthwhile, I wouldn’t go”.

Staff
Only 38% of staff felt there was always a sense of shared responsibility and shared decision making. However over 46% of staff felt that this was usually the case and the remaining staff felt there was no shared responsibility.

Fostering social context and relationships

Persons with dementia
PWD stated how welcome they felt at each of the programs, and company was extremely important. “I feel like I am part of the group” and “there is always someone to talk to and I like to talk.” One client used the term congenial repeatedly when asked about the group “ they are a congenial crowd, I feel as though I have known them for a long time, knowing that we are all in the same boat makes it feel good, very congenial”. Some respondents commented on how their life had changed. “I was a loner and did not mix, but I like it here.”

Going out as a couple was also valued by PWD, “it gets me out of the house with my husband as a couple, we are not snapping at each other, we have a break from each other in the house together, we have met new people” Another said, “I like it that my husband can come, I rely on him because I don’t drive anymore”.

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Carers
Joining a group, making new friends and sharing similar issues were highlighted by carers. “We were welcomed and able to make new friends and meet informally” was one comment, while another commented on the invitation, “we got an invitation and introduced to others, it was a relief to meet others in a similar situation.”

The loss of their former social life as a result of a dementia diagnosis was an issue for carers. “We had lost our social life, we had no social life until Coffee Break, now he wants to go every day.” Focus group participants commented on how motivated their partners were on the respite days, “he/she gets up and dressed and is always ready to go, they really enjoy the company.”

Doing something as a couple was also highly valued by the carers, “we can go out as a couple and it does not matter about the manners.”

Staff
Over 85% of staff felt that the programs fostered social relationships and new networks. Staff commented on the importance of giving clients and carers “the opportunity to share moments together as they may have done in the past”, and “giving people the opportunity to do ‘normal things’ such as going out for coffee. Also “giving carers a network”, However they were keen to see more after hours and weekend services to improve the opportunity to socialise more ‘normally’.

Enhancing communication
Persons with dementia
PWD commented repeatedly on the genuine communication and appropriate contact. Participants commented on the attentive listening skills of staff “the staff are good listeners, and they know you, and your life,” another person added, “they listen to me, they do not push me aside, they help me, check whether I am upset or not”.

PWD valued how staff managed their time, “if they are busy, they negotiate a time and say perhaps you can do this until I get back to you,” and “they talk to me caringly about my life, it is about me, people in my life.”

Carers
Carers welcomed the ability to communicate as a group over coffee with the staff member, “we are all in the same position, I feel free to chat when I go, when I went home I realised that I wasn’t the only one”. Over 90% felt that the staff had a good understanding of what they were going through with 76% feeling staff appreciated their role as a carer. One carer wrote the following about staff communication and relationships, “staff are attentive, loving patient, handle difficult situations well, they give us options, and go along with our partners, they are innovative.”

Staff
Staff had mixed responses regarding the communication processes within the activities. On one hand nearly 70% felt the communication was always sensitive, authentic and affirming. However, the comments described the “need for more interaction with individual clients” and “the need for the staff not to be the show, but part of the show”. Others wanted to “see more engagement with clients during the social part of the program” and “more empathy with each one if possible, know how they are feeling, listen to their requests”. Staff requested more dementia training.

Meeting physical and personal needs
Persons with dementia
Having a cup of tea or coffee and a snack at no cost was highly valued by PWD. This was particularly evident in the coffee group, they were able to go out, have a hot drink with a muffin or scone and there
was no cost. “The fact that it is free is really important, there was only 85c left last week after paying the bills, wouldn’t even by a cup of coffee, it is a good outing for us.”

Carers
Like the PWD, carers valued having coffee or tea out at no cost. Carers like the fact that the venues had plenty of room and their physical needs were taken care of “it relieves me of the burden of the ‘wheelie walker’.” Another carer commented on his hearing impairment saying “I find it difficult to hear, so just sit back, noise is an issue, however she enjoys it and that is what is important to me.”

Staff
Over 93% of staff felt that the PWD and Carer’s physical and personal needs were met in a sensitive and positive way.

Developing a therapeutic alliance

Persons with dementia
Comments about trust, openness, care and honesty were mentioned by most PWD during their interviews. One respondent wanted the author to “thank all the girls, I am always grateful, if I did not have them I would be down,” another person commented on “staff doing a damn good job, they get me out and I feel good”.

Carers
Carers in the coffee group welcomed the opportunity to “chat with others in the same situation,” and “sharing stories and knowing that we can just chat about our interests.” They are “comfortable with the conversation”. Being treated as a valued human being also provided carers with hope, “company, she lives alone and loves someone to talk to, she is treated like a valuable member of society, worthwhile and wanted.”

Hope also meant having a break and release of the worry of their partner. One carer stated “I feel a huge weight lifted off my shoulders, it gives me a chance to catch up on appointments”, another carer said “I can relax by myself, go out if I want or just put my feet up and read without any worry as to what he is doing”.

Staff
Likewise, over 90% of staff felt that there was genuine empathy and unconditional positive regard shown to PWD and their carers. They felt activities such as art 'enhanced self –worth' and there was a sense of achievement when they completed their piece of work.

Valuing expertise

Persons with dementia
PWD felt their contribution was valued however most were keen to go along with what was offered. One of the art participants valued the staff respecting her art work.

Carers
Carers in the focus group felt that their role as carers was valued however to them it was more important that their partners were doing something where their interests and expertise were valued. This was expressed in their desire to have a men’s group that focused on their interests and within their capabilities.

Staff
Expertise in dementia was the most common comment from staff. Almost all staff (90%) felt that the expertise and knowledge of all stakeholders was valued however as discussed earlier, staff certainly expressed the need for more training to work with PWD, specifically person-centred care.
Discussion

The findings demonstrate that GHACS’ innovative respite services are mostly aligned with Bamford’s components of person-centred care. Results indicated that the services respond well to components associated with respecting individual values; enhancing psychosocial well-being and communication; fostering a social context and relationships; meeting physical needs; developing a therapeutic alliance; and valuing expertise. Components requiring further development were: promoting autonomy and a shared sense of responsibility. People like choice and input into their activities and programs, furthermore, they feel a sense of responsibility and the power between staff and client is more equitable.21

Three key themes arose from the data, analysing the characteristics of person-centred respite care within the context of the current study.

Fun

A happy, welcoming environment where all stakeholders can have fun, laugh together, share stories and tell a joke are claimed to have positive effects on memory, sociability and potentially self-esteem.22 Carers noted how happy their relatives were prior to and after the activity. Their day was much easier and the activity resulted in a happier and contented relative.

Going out and having fun as a couple was desired by carers and PWD. Molyneaux et al. observed the notion of striving to maintain the balance in their relationship as soundly as possible.23 Staff also valued the fun they had facilitating activities and while most did not recognise their contribution, the PWD and carers appreciated the attributes of staff and their participation.

Friendship

Welcoming staff that are enthusiastic, sociable and highly aware of newcomers needs are key attributes of person-centred care. The skill to introduce new people and foster friendships to promote conversation was highlighted. Equally important was authentic communication demonstrated by a genuine interest and concern for the client’s wellbeing and life. Carers acknowledged the loss of friendships and their former social life.

Enduring friendships, a strong facilitator who could solve problems rather than talking about them, while recognising and respecting how much knowledge and wisdom carers have, are important components of effective carer support groups.24

Freedom

Freedom to be creative, sing, paint, have time for ‘me’ were expressed by PWD and carers as significant positive attributes. Creative expression is a basic human need and maintains our sense of wellbeing. Creativity transcends the isolation they may be feeling and brings pleasure and satisfaction.25

Carers welcomed the freedom of being able to go out as a couple and not worry about what their relative said, their manners or the mess (crumbs) from a muffin or scone. ‘To be free’ that is, free to be themselves, to pursue their own interests, and to not be in the role of caregiver was identified as key components of person-centred respite, focusing on strengths and capabilities.26,27

The present study is limited, primarily due to the small number of respondents. While the results cannot be generalisable due to the study being undertaken in one regional area, it is probable the flexible innovative respite services in other settings would have the same outcome.

It is evident that these innovative unfunded programs align with person-centred approaches. They are very different to the traditional planned activity programs and day centres and meet a much desired need. Funding that ensures PWD and their carers have access to quality respite programs that are appropriate to their needs is critical. There is a significant gap between policy and practice and the
literature highlights the need to build evidence around rural and remote respite options and quality service delivery in these communities. This study addressed both of these issues and provided evidence about the lack of consumer choice and flexibility in current funding for dementia respite care.

Acknowledgments
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Conference recommendation
That policy and funding reflect the current need for evidence informed innovative person-centred (consumer directed) respite programs for people with dementia and their carers.

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