

Caring for carers

Evaluation of a support program for carers of people with dementia

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Caring for Carers was initiated by the Brotherhood of St Laurence in 2009 as a pilot program to assist people caring for someone with dementia in the community. It provided carers with 8 weeks of training and 24 weeks of follow-up support, delivered by project workers experienced in community dementia care. Over three phases it developed into a personalised program of training and ongoing support. Using action research methodology in a program logic framework, the evaluation gathered evidence from stakeholders, which was fed back to enable continuous improvement in program design and delivery. At the end of the program, an overall assessment was made of its impact on carers' experiences and wellbeing.

Key points

- Carers reflected positively on the program and drew a range of benefits from the different components of training and support. They valued most highly the regular one-on-one contact with a trained professional in the home. Many felt that the program was of considerable and lasting benefit and some described the program as life-changing.
- Carers were provided with advice on how to manage difficult dementia-related behaviour. They were able to trial techniques to assist with daily activities such as showering, dressing and shopping. Through these techniques carers felt that they were better able to maintain their caring role. Advice on managing behaviours such as 'shadowing' and repetitive questioning was also of benefit.
- Carers valued the information provided by the project worker. Information and literature on dementia, dementia-related behaviours, diversional therapy techniques, advanced care planning, additional support services and residential care equipped the carers with the knowledge to make informed decisions, which they felt improved their ability to care. With this information and ongoing support, carers were able to better prepare for events such as a move into permanent residential care or to take up additional help as required.
- As a result of the program carers increased their use of, or used for the first time, additional support services such as respite. These services further contributed towards carer and care recipient wellbeing.
- Sustained contact over 32 weeks established an important dialogue between the carer and project worker. This allowed daily issues and concerns to be discussed and addressed collaboratively and in a timely manner. Many carers commented that this was an empowering experience.
- The ability to talk openly and in a familiar environment also provided emotional support and relieved some of the stresses of caring. Carers felt able to discuss issues with the project worker that they could not raise with family, friends or formal care / support workers. This provided carers with an important outlet for feelings of burden and stress.
- The dialogue between the carer and project worker was extended to include formal care workers. This made care managers and respite service staff aware of issues that were previously unknown, subsequently enhancing formal care plans and respite services.
- The action research methodology allowed shortcomings in program delivery to be addressed as they arose and changes to be made accordingly. Thus, by the third and final phase the program represented an effective, multi-component model of carer support, tailored to the individual needs of carers. C4C proved able to address the complex issues that shape the caring relationship, primarily for those caring for a partner with dementia.

Background

Informal carers, usually family members and friends, play a crucial role in the provision of community dementia care. As dementia rates rise, and as community care continues to be prioritised, reliance on these carers is expected to increase. Yet the primary carers of people with dementia experience high levels of stress and burden. This is caused by a complex combination of factors, but dementia-related behaviour is considered to be a prime cause of stress. At the same time, programs to support the needs of dementia carers are few in number and vary in design and efficacy. With this in mind, BSL set out to improve support for carers of people with dementia. It used the STAR-C program, a clinical and behaviour therapy approach trialled and tested in the US state of Oregon (Teri et al. 2005), as the basis for exploring and further developing effective means of carer support.

BSL began delivering the pilot phase of the program in 2009. This included an 8-week training period, followed by 24 weeks of follow-up support. This structure was maintained in Phases Two and Three of the program. The training and ongoing support was provided by project officers trained in diversional therapy and with extensive experience of community dementia care. Following feedback after the first phase, the program was adapted to better suit individual carers. This involved a shift away from the clinical and prescriptive STAR-C approach to one that allowed individual carers' needs and particular issues to be addressed as they arose. The focus on individual carers emerged as a major feature of the program.

All 25 carers involved were caring for a family member with moderate to severe dementia, and most had been caring for more than two years prior to commencing the Caring for Carers program. This had shaped their individual needs and required an adaptive and flexible approach by the project officers.

The research

The Caring for Carers program was developed and evaluated using an action research methodology in a program logic format. Stakeholders' views and feedback were used to test, reflect on and evaluate program developments, allowing continuous improvements in program design to be made.

As the program developed so too did the evaluative methods. The move away from the prescriptive and clinical approach of Phase One was matched by changes and refinements in data collection techniques.

The clinical and statistical methods for measuring carer wellbeing were discontinued after Phase One. A comprehensive, three-stage interview schedule was developed to track and documents carers' reflections throughout the entire program.

Carers participating in Phase Two and Phase Three were interviewed on three occasions, rather than one as was the case in Phase One: at the commencement of training, after the training stage and during the follow-up support period. This schedule enabled carers' attitudes towards and experiences of caring to be assessed over an extended period, the reasons behind use of additional services to be explained and care experiences to be compared in greater detail. Along with detailed carer backgrounds, this made it possible to appreciate the care history and relationship, the barriers to carer support and the impact of the program on carers' wellbeing. Analysis of carer satisfaction surveys provided additional evidence for the assessment of the program. Interviews with the project officers were conducted on a similar schedule.

A care manager focus group yielded valuable information on the interaction between the carers program and formal care delivery and revealed the benefits of improved communication between carers, project officers and care managers.

The reflective methodology and the ability to refine techniques for gathering information provided a firm basis for determining the outcomes and effects of the program over its two and a half year timeframe.

Research findings

Overall, carers responded positively to Caring for Carers. Most reported that the program had helped them to better manage their caring role. They could identify components that they found useful, such as the practical advice or the behavioural therapy techniques. The one-to-one support was the most beneficial aspect of the program according to carers. This personalised approach allowed the particular needs of individual carers to become the focus of training and ongoing support. For instance, some were in more need of emotional and personal support, whereas others drew more benefits from the practical advice and solutions to various problems. In all cases the program was tailored according to carers' distinctive needs.

Some of the carers commented that the Caring for Carers program was transformative. For these carers, the program represented a major turning point in their lives, in spite of the continuing health challenges which

their loved one faced. It greatly improved their wellbeing, enhanced their experience of additional support services such as respite and enabled them to better understand and manage the demands of the caring role.

Program developments

Over the program's three phases a number of changes were made. Both partner carers and adult-children carers were involved in the first phase. The differences that emerged between carer groups resulted in the program being directed solely towards partner carers in subsequent phases. The topics covered during the training stage were also adapted according to carer need. In Phases Two and Three more emphasis was given to the issues that carers raised themselves. This represented a shift away from the clinical and prescriptive approach to a person-centred focus which evolved to meet the diverse needs of individual carers. Carers commented positively on these developments.

Multi-component program

Other research evidence suggests that multi-component programs are the most effective way to enhance carer wellbeing (Gallagher-Thomson & Coon 2007). The Caring for Carers program evolved to support multiple methods and approaches to dementia care. These included behavioural and diversional therapy strategies, emotional support, practical advice and information. This allowed individual carer needs to be taken into account and different issues to be addressed as they arose.

Information

Carers valued the information and literature provided by the project workers, reporting that it helped them understand dementia and dementia-related behaviour and improved their knowledge of the services available. Such knowledge also allowed carers to make better informed decisions, and many described this aspect of the program as empowering.

Emotional support

Carers found that the program provided them with emotional support that was not available elsewhere. Given the personal and social demands of caring, this emotional support was highly valued by most of the participants.

Other support services

A clear majority of carers increased their use of respite care as a result of the program. Given that respite is considered a vital service for carer wellbeing, this represents a significant outcome.

Communication and collaboration

The program facilitated a vital dialogue focused on carers' needs. Carers were able to discuss with a project worker issues that they did not feel comfortable discussing with family members, care managers or other service staff, enabling them to address problems that would have simply remained hidden or unspoken. Collaboration between the carer and project worker allowed carers to feel more in control and proved effective in enhancing problem-solving skills. All of the carers commented that this conversation in itself contributed to increased wellbeing.

Project workers initiated dialogue about carers' needs with care managers and this improved formal care plans. Collaboration between project workers, care managers and respite staff was also evident and helped to improve formal care services.

External factors

A number of factors external to the program, such as family and care history and the progression of dementia, had a bearing on program outcomes. However, the person-centred approach provided helped carers deal with these. For example, in a number of cases the program helped carers overcome previous negative experiences of care services. It also helped some to prepare emotionally and practically for the care recipient's transition into permanent residential care when this became necessary.

Conclusion

Over its three distinct phases and through the input and reflections of stakeholders—carers, project staff and formal care workers—the Caring for Carers program evolved into an effective and person-centred approach to dementia care. It also facilitated communication between carers and formal care workers, which helped to integrate the variety of services made available to carers and care recipients. The person-centred approach to dementia carer support developed throughout is the main reason for the program's positive effect on carer wellbeing, and places the BSL in a position to further expand this approach.

The research findings justify the action research method as a way to improve program design and delivery and as an effective tool for evaluation. This is reflected in the continuing improvements made to the program and the improvements in data collection. It shows also how stakeholders' views can be effectively integrated into program development and evaluation so as to address shortcomings and enhance outcomes.

The findings also support a number of suggestions which relate to extending and expanding the program, further integrating the program into current BSL community care services, intervening earlier to support carers, introducing formal carer support plans, selecting staff and assessing the cost benefits of the program.

References

Gallagher-Thompson, D & Coon, DW 2007, 'Evidence-based psychological treatments for distress in family caregivers of older adults', *Psychology and Aging*, vol. 22, no. 1, pp. 37–51.

Teri, L, McCurry, SM, Logsdon, R & Gibbons, LE 2005, 'Training community consultants to help family members improve dementia care: a randomized controlled trial', *The Gerontologist*, vol. 45, no. 6, pp. 802–11.

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For further information

The full report *Caring for carers: evaluation of a support program for carers of people with dementia* (PDF file, 387 KB) by Ashley Carr, Helen Kimberley and Monica Mercieca may be downloaded from the Brotherhood of St Laurence website.

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