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Promoting respite to carers of people with dementia: a case study of social marketing effectiveness for a hard-to-reach audience

Abstract

Design/methodology/approach - This case study describes the development and approach of a theory informed social marketing intervention. Via formative research, we gained an indepth understanding of a hard-to-reach and vulnerable group (carers of people with dementia). The resulting intervention informed, persuaded, and supported carers to rethink the use of respite addressing specific barriers to service use. The intervention was evaluated using a naturalistic effects model.

Purpose - Despite a high need for respite, carers of people with dementia are often low users of available respite services. The reasons for this are complex, including knowledge, attitudinal, behavioural and systemic barriers. In the context of an aging population, effective strategies to support respite use by carers of people with dementia are needed.

Findings - Carers of people with dementia who were exposed to community level campaign activities and also self-selected to take part in tailored coaching showed improvements to their respite knowledge, attitudes and self-efficacy. Intention to use respite, and levels of personal gain from caring also increased. In contrast, carers only exposed to informational activities experienced negative changes to their respite beliefs and their sense of role captivity.

Practical Implications: Social marketing can be used to support carer respite knowledge, attitudes, and service use behaviours in carers of people with dementia. The case study highlights an untapped role for social marketers to work in partnership with health professionals to support improvements in aged care services.

Promoting respite to carers of people with dementia: a case study of social marketing effectiveness for a hard-to-reach audience

BACKGROUND

Dementia is a degenerative neurological syndrome which leads to profound physical and cognitive deficits. While 34% of people with dementia require institutional care (Australian Institute of Health and Welfare, 2007), the presence of a co-resident carer increases the likelihood that people will be able to live at home longer (Banerjee *et al.*, 2003). Caring for a family member with dementia can be a positive experience (Carbonneau *et al.*, 2010), however, caring is associated with stress and physical disability and can be more stressful than caring for an older person without dementia, particularly if the carer feels trapped (Bertrand *et al.*, 2006).

The provision of respite is consistently identified by carers as one of their critical unmet care needs, yet the overall proportion who use respite and other support programs tends to be low (e.g. 31%) (Bruen and Howe, 2009). In Australia, and likely worldwide, this is influenced by numerous complex and interacting factors. First, the dementia services care environment is complex and fragmented, with carers (and people living with dementia) experiencing absence or delays in diagnosis, poor communication and referrals to support services (Boustani *et al.*, 2008). Second, carer's use of support services can be influenced by perceptions of poor quality, lack of availability, high cost, a lack of flexibility in service arrangements and expectations that negative outcomes will occur as a result of use (Phillipson *et al.*, 2014, Fielding *et al.*, 2012). Finally, some carers of people with dementia associate the use of respite and support services with guilt and failure or not fulfilling family responsibilities which create additional barriers to service use (Fielding *et al.*, 2012, Phillipson *et al.*, 2014).

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Carers of people with dementia have consistently reported that respite provides them with 'more than just a break' (Bruen and Howe, 2009). Respite includes day care services that provide opportunities for people with dementia for social participation and mental stimulation (Phillipson and Jones, 2012); in-home services that ensure safety during caregiver absences (Phillipson and Jones, 2011b) and residential respite that support carers to provide better care and eventually support smoother transitions to permanent placement (Phillipson and Jones, 2011a).

There has been some contention regarding the strength of the evidence concerning burden alleviation (Arksey *et al.*, 2004) as well as the impact of respite use to delay institutional care (Parker *et al.*, 2008). Some have concluded this may because carers have accessed respite interventions too little and too late (Gaugler *et al.*, 2005). Others have suggested that evaluation studies have not focused sufficiently on the important interrelationship between respite access and a carer's ability to access other clinically effective carer support interventions (National Institute for Health and Clinical Excellence, 2006). This is important, given the effectiveness of other interventions which are available to support carers and people with dementia living in the community (Vandepitte *et al.*, 2016). Psychoeducational interventions and multicomponent interventions have led to positive outcomes for carers and delayed permanent placement of care-recipients in residential care (Vandepitte *et al.*, 2016).

Respite in Australia

Australia commenced a program of major reform of the aged care system on July 1, 2015 (Creswell, 2017). This included changes in the administration and funding of respite services for older Australians, the amalgamation of previous programs and packages under the Commonwealth Home Support Program and a transition to Consumer Directed Care (Department of Social Services, 2014). In the Australian context, access to all service types is

possible. However under the new reform, this occurred via a number of different pathways and programs (Phillipson et al. 2018). While this reform aimed to improve service delivery for older people, it also led to increased confusion for people with dementia and their carers over 65 years of age, as well as difficulties for people with younger onset dementia as they attempted to navigate a service system in transition (Creswell, 2017).

In the midst of these reforms, a complex community-based intervention was required to improve access to, and utilisation of, respite by carers of people with dementia. To be successful, formative research suggested that the intervention would need to address both the individual beliefs and behaviours of carers around the use of respite, as well as look to the fluid and changing aged care system in which these behaviours existed. Social marketing, with its strong emphasis on stakeholder engagement and flexibility of program design responsive to audience needs, was ideally placed to guide intervention development (NSMC, 2016). It was also reasoned that the high awareness and information needs surrounding a changing system, were best addressed through a strong promotional approach tailored to the diverse audience of older and younger carers, some with high digital literacy, and others with low digital literacy and/or access (Kuerbis et al. 2017). Social marketing has previously been effectively used in issues affecting older communities, used to improve health and wellness of older adults living in the community (van Esch et al., 2019, Fujihira et al., 2015), and to raise awareness and challenge the stigma of dementia in the community (Devlin et al., 2007). The National Social Marketing Centre identified eight benchmark criteria that contribute to the success of social marketing programs (NSMC, 2016) based on six earlier criteria developed by Andreasen (2002). Benchmark criteria include use of target audience orientation, research/insight into the target audience, segmentation, consideration of the competition, consideration of the benefits and costs (exchange), use of behavioral theory,

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behavior change focus, and use of a mix of methods (product, price, place and promotion). Research has shown that interventions applying the benchmark criteria can be effective in changing behaviors in individual consumers and patients, and also 'upstream' target audiences of professionals, organisations and policy makers (Stead et al. 2007); and that those interventions addressing more SM criteria are more effective than those utilising fewer (Carins & Rundle-Thiele 2014, Xi et al. 2016). However, Schmidtke et al. (2021, p. 240) report that too few interventions described as SM can 'apply and clearly report' the application of these benchmarks, noting that this may be because many SM benchmarks are highly abstract. They see benefit in the reporting of clear examples of SM practice to overcome this conceptual limitation.

In the absence of effective strategies to support respite use by carers of people with dementia, NSMC criteria were addressed within a social marketing planning process (Kotler and Lee, 2008) to develop a cohesive and persuasive multicomponent intervention -

. This case study describes the development and implementation of the intervention, with a focus on the operationalisation of these benchmarks. Evaluation detail is available in

INTERVENTION DEVELOPMENT

NAME BLINDED aimed to improve knowledge about, attitudes toward and uptake of respite by carers in the BLINDED community.

A. Target audience orientation

The project aimed to re-position respite as an integral and 'normal' part of caring that has positive benefits for people living with dementia *and* their carers and therefore should be incorporated early in the care trajectory. A secondary aim was to improve respite service provision by educating service providers on the needs of carers of people living with dementia and enabling providers to better meet their information and respite service needs.

B. Research and Insight

The target audience was identified as people with dementia and their carers living in the BLINDED region with an unmet need for respite. This included spousal caregivers and adult child caregivers.

Secondary populations included providers of respite services, dementia advisors, and health professionals serving carers and people living with dementia.

In 2014-15, a baseline survey was conducted with 84 carers to assess knowledge, attitudes, information seeking behaviors, and unmet need for respite. The majority of carers sought respite service information (86%) but also reported an unmet need for respite services (73%)

. Carers reported limited use of government support services to find out about respite, and a preference for interpersonal information sources, including local doctors (65%), carer support groups (49%), and family and friends (46%).

Stakeholder Consultation

Consultation was conducted with forty stakeholders to inform the development of the project and to pre-test materials. Stakeholders included carers and carer support groups, service providers, health professionals, researchers and government organisations involved in providing care and services for the priority population. Two specific groups, a carer reference group (n=5) and a service provider reference group (n=5) were formed and met on at least three occasions to inform and pre-test intervention materials. See Table 1 for details of all stakeholder consultations.

Table I. Stakeholder Consultations

[INSERT TABLE 1 HERE]

C. Exchange and competition

In developing insight into the target audience, we sought to understand what competes for their time and attention, and what contributes to low uptake of respite services.

Barriers to Respite

Previous research had illuminated a range of barriers including carer beliefs regarding poor service quality, guilt or the possibility of negative outcomes, a confusing and fragmented dementia services environment, lack of availability and flexibility in service provision, and poor communication and referrals to support services (Phillipson *et al.*, 2014, Neville *et al.*, 2015).

Based on this research, strategies were developed to minimize barriers and the competition. Respite was re-positioned to challenge beliefs such as guilt. Barriers such as difficulty finding information and navigating the service system were reduced. Results of the formative research confirmed the need to involve providers of, and referrers to, respite services, both as stakeholders and secondary target audiences.

Benefits of Respite

Ideally, respite use commences and continues in different forms throughout the various stages of the dementia trajectory (Gaugler *et al.*, 2005). It should form part of an ongoing plan to maintain carer health and wellbeing (National Institute for Health and Clinical Excellence, 2006). In the formative research, carers and people with dementia identified the need for respite that is affordable, reliable, flexible and tailored to meet their needs. Based on this, benefits of using respite were identified for both members of the dyad including:

- supports the social participation of people with dementia and their ability to pursue • activities of interest;
- provides carers and people living with dementia with an experience of different care • facilities that may be required in the future;
- gives carers time to look after themselves and their own needs such as going to work, an appointment or a volunteer commitment;
- prevents social isolation by providing carers with opportunities to meet with friends or • attend a support group;
- helps carers keep healthy and improves the quality of care they provide; and •
- sustains carers so they can continue their caring role with the person with dementia • staying at home longer.

D. Behavioral Theory

The primary theoretical framework underpinning NAME BLINDED was Andersen's Behavioral Model of Service Use, which proposes that service use is influenced by demographic; social structure and health beliefs (predisposing characteristics); community and personal resources (enabling or impeding factors); and evaluated and perceived need factors (Andersen, 1995). These concepts informed the selection of the intervention components, ensuring relevant behavioural, social and system factors were targeted. More specifically, the activities to improve carer knowledge of and attitudes towards local respite services included a website and a respite coaching program and positive promotional messages (e.g., potential benefits of early and regular respite service use for the people with

dementia and carers) disseminated via multimedia and interpersonal channels (e.g. presentations at community events and carer support groups, and for respite service providers and health professionals). The activities to facilitate carer use of respite services included provision of practical resources such as navigational aids to local services on the website and a tailored coaching program. See Figure 1.

[INSERT FIGURE 1 HERE]

Figure 1. NAME BLINDED activities developed to address needs of carers of people with dementia at various stages

E. Behaviour change orientation

Based on the results of the formative research and consultation with stakeholders, awareness, belief and behavioural objectives were determined for each target audience. See Table II.

Table II. Knowledge, belief and behavioral objectives for target audiences

[INSERT TABLE II HERE]

F. Method Mix

Product

Core benefits for the target audience in relation to the product were: carer longevity; positive experiences for care recipients; a break from caregiving responsibilities; ability to pursue own activities (including work); substitute care in an emergency; and a supportive 'stepping stone' to future permanent placement. Respite was the 'actual product' including short-term stays in residential aged care facilities; cottage respite; center-based respite services; in-home respite; emergency respite; carer support and counselling; or other respite strategies such as mindfulness. While we did not have control over the actual product and

were reliant on the current system to deliver the proposed benefits, we sought to achieve service improvement through the conduct of service provider workshops (described below). Augmented products developed in response to target audience research and stakeholder consultation included the website (BLINDED) and associated materials, the NAME BLINDED coaching program and service provider workshops.

NAME BLINDED Website

The website promoted respite as a resource for successful caring, as well as arming people with dementia and carers with the knowledge and skills to negotiate positive respite outcomes. It provided:

- information on respite services, including a directory of respite services in the two • regions;
- articulated pathways on how to access respite with links to searchable directories of respite services;
- a decision guide () and checklists for choosing specific respite jorver. services;
- videos on positive respite experiences;
- key contacts and support group lists;
- an events calendar and news blog; and
- a carer discussion forum.

Printable versions of key resources were available to download and were promoted to primary health care nurses, assessment services and respite service providers to distribute to their clients. Prior to launch, the website was tested with four carers of people with dementia in a usability testing laboratory. Improvements were made to navigation and design features.

NAME BLINDED coaching

The coaching program was developed specifically for a segment of the target audience who needed additional support to navigate the complex respite service system. This psychoeducational program was developed based on motivational theories and psychological approaches (Baltes and Baltes, 1990). Key features included:

- identification of participants' personal goals, strengths, and values which may facilitate respite use;
- identification of potential benefits and barriers to using respite;
- activities to help determine participants' respite needs and preferences;
- support to find information about local respite services; and
- discussion and support to implement 'informal respite strategies' such as mindfulness and communication strategies.

Coaching program activities aimed to:

- increase knowledge about respite services and strategies; encourage decision making about respite use;
- improve communication between the carer and the person with dementia as well as service providers; and
- enhance intention and capacity to use local respite services and strategies.

Individualized coaching was delivered by trained health professionals in the participants' homes. The number and length of coaching sessions was flexible and based on participants' preferences. A coaching workbook was developed to accompany the tailored program, and a facilitator manual was also developed with train the trainer modules.

NAME BLINDED Service Provider Workshops

Four service development workshops were conducted in two regions targeting respite service providers and referrers (such as primary health care nurses). The workshops focused on improving the quality of information about respite services available to people living with dementia and their carers; and improving service quality based on the needs and wants of people with dementia and their carers. The 'flexibility in respite' tool to audit service quality and service provider training workbooks were produced, and sessions were evaluated with post-workshop surveys. These system-level strategies were founded on the knowledge (from formative research) that information about respite services needed to be up to date, timely and address the concerns of carers, as well as the respite services themselves being more responsive to the needs of carers in their timing, availability, activities, and flexibility (Phillipson, Jones and Magee 2014).

Price

For NAME BLINDED, intervention strategies and resources were developed to address barriers identified in formative research and stakeholder consultation (see Table III). Barriers included perceptions of poor respite service quality, lack of availability, low flexibility, high monetary cost, carer guilt and perceptions of negative outcomes, as well as barriers in terms of finding information and navigating the aged care system.

 TABLE III: Strategies to mitigate barriers to respite perceived by carers of people with dementia

[INSERT TABLE III HERE]

Price strategies included:

promotion of government subsidized services and 'free' strategies such as informal respite;

- use of positive respite experience 'case studies' via website and media releases/stories; and
- distribution of a services directory to promote and enable access.

Respite service providers were also engaged in education and motivational sessions to reflect on how they might improve their respite offerings and information and set goals for service improvement over the next 12 months.

Place

Over twenty educational presentations were made to carer support groups, community groups, primary health care nurse network meetings, aged care assessment services and respite service providers. Messages were delivered to the target audience via these groups and service providers, the local and carer media, and via online promotions (e.g. ww.dementiais.com, local council, Facebook). Place strategies also included promoting key messages and distributing project resources (e.g. bookmarks, fridge magnets fliers, printed service directory) throughout the community.

Promotion

The brand 'NAME BLINDED' aimed to promote an exploration of respite options, reconsideration of how respite might benefit them, and the benefits of earlier use. It also encouraged people who had a previous negative respite experience to re-think what might work for them and try again. The brand was expressed via a logo and motivational messages (promoting key benefits) as well as secondary messages to challenge competitive beliefs (such as beliefs that respite is a sign of failure or not coping). Creative images (and audiovisual case studies) used on the project website and as part of the marketing materials illustrated a variety of positive and engaging respite experiences and aimed to appeal to the target audience of younger and older adult carers. Key messengers included project staff, dementia service providers and advisors, general practitioners and primary health care nurses, and local and other targeted media (e.g. carer media). Messages were also promoted via a dedicated project website (BLINDED), newsletter, and via community events. These project activities had a dual purpose which included promoting the key messages of the intervention, as well as endorsing and promoting referral to other intervention activities. Various materials were developed, including bookmarks; fridge magnets; flyers; and information brochures, to aid the promotion of the project.

[INSERT FIGURE 2 HERE]

FIGURE 2: NAME BLINDED promotional collateral

INTERVENTION EVALUATION

A logic model was used to support monitoring implementation integrity

See Figure 3. The model hypothesized that intervention activities/strategies would increase carer knowledge of local respite services, improve beliefs about the benefits of respite and respite services, and improve self-efficacy for finding information about, and accessing, respite services. It was envisaged this, along with improvements in local respite information and services, would lead to increased use of respite and intentions to use respite, as well as reducing unmet need for respite in the local community.

[INSERT FIGURE 3]

FIGURE 3: NAME BLINDED program logic model

All study protocols and materials were developed with input from Carer and Health Professional Reference Groups with an emphasis on minimising the risk of psychological distress to any participants. All participants in the study provided informed written consent,

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and all were provided with a 'Carer Support Services' information sheet which provided carers with information regarding services that could provide immediate support and advice regarding referral and providers for local relevant counselling services; contacts for local carer support groups; and details for assessment of the person with dementia for whom they provide care. The final protocol was approved by the University Human Research Ethics Committee (XXX/XXX).

To evaluate the impact, we conducted a naturalistic effect evaluation (Windhorst et al. 2019), where resources were offered to participants who then accessed and used the components they felt relevant to them, including the respite coaching. This evaluation model aims to determine the effectiveness of the intervention under 'real world' conditions and as such, precludes randomisation and the standardisation of interventions which is usual in controlled trials (Green and South 2006). In summary, a convenience sample of n=70 carers were recruited and surveyed over a six month period in 2015-16 to establish a baseline for knowledge, attitudes and use of respite for a cohort of carers in the region. Carer perceived need for respite, burden and self-efficacy were also assessed. Process monitoring recorded reach and engagement with the program strategies between 2016-2017. At program completion, a follow up survey was administered over three months in 2017 with n=44/70 responding.

All respondents reported participation in and exposure to NAME BLINDED media, information, and education during the intervention period. At follow up, few positive results were reported on the assessed carer variables for the cohort over time. However, post-hoc sub-group analyses found those who also self-selected to receive active support (provided through coaching) (n=18), showed improvements to their respite knowledge, attitudes, and self-efficacy (p<0.05). Intention to use respite, and levels of personal gain from caring in this sub-group also increased (p<0.05). In contrast, carers who only participated in the informational/educational aspects of the program (and did not self-select to the respite coaching), experienced negative changes over time to their respite beliefs and 'role captivity'. Follow-up contact with several service providers found few had made any improvements to their respite service information or programs. Rather, most reported they were focused on coping with the turnoil of a transitioning aged care and referral system and had been unable to action any of the goals set to improve their respite services. Overall, evaluation of the pilot study suggested that passive respite information and educational strategies were insufficient on their own, and that more active supports (tailored respite coaching) were also needed to address observed carer decline over time. Further details concerning data collection, analysis and results from the evaluation have been reported elsewhere

IMPLICATIONS FOR PRACTICE

This case study details the practical application of the social marketing benchmark criteria to support a complex multi-pronged intervention promoting respite knowledge, attitudes, and service use behaviours in a vulnerable and hard to reach group: carers of people with dementia. It has utility to highlight the role of social marketing in guiding interventions designed for the aged care market. It also addresses a gap in the social marketing literature by clearly reporting the application of abstract SM benchmarks and how they were employed to translate audience insights into an effective integrated mix of strategies.

Applying carer and aged care audience insights

It is known that older people can be particularly vulnerable when making health and care system service choices due to a lack of awareness of the alternatives available to them (e.g. Henderson and Willis 2020). In Australia, this has been due in part to a failure to design aged care services promotions that are appealing and accessible to an older audience who are

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living with considerable health needs (Phillipson, Low and Dreyfus, 2019). This case study highlighted the value of intensive, local, grass-roots local campaigning involving community education sessions and health professionals as the primary channels to re-position beliefs about respite services as beneficial and positive for both carers and people with dementia. These interpersonal channels, whilst more intensive to use, are favoured by older audiences (Stanziano 2016) and were critical in achieving high reach and contact with the older carer audience. This type of campaigning was in stark contrast to the existing government communication strategy which relied almost entirely on passive posting of web-based information and had been critiqued, amongst other things, for failing to address carers as an audience within existing information sources (Phillipson, Low and Dreyfus, 2019). The case study again underscores that governments and service providers must commit to more active engagement and supports for vulnerable population to gain equitable access to health and care services that support their wellbeing.

Significantly, despite good reach, the intervention was only effective in supporting improvements in respite knowledge, attitudes, & service use intentions, carer self-efficacy and levels of personal gain when carers opted to receive more intensive supports through a dedicated coaching service. Application of the social marketing benchmark criteria was useful to prompt the need for this augmented product as an essential part of the mix of strategies (NMSC 2016). This need was also identified by the project's Carer Advisory Group in acknowledgement of the wide-ranging impacts of caring for some with dementia including its effect on their family member's function, personality and behaviours, the degenerative nature of the condition, and the eventual need (for most) for physical and emotional support – day and night, seven days per week, usually over a period of years (Mace and Rabins, 2017). Again, this case study underscores that the numerous barriers that define

an audience as 'hard to reach' will likely require professional expert supports and considerable time to overcome.

To develop the carer coaching program, insights about the older caregiver audience also needed to be applied from best practice psycho-educational interventions. This included structuring the respite coaching program to address: multiple caregiving needs (Brodaty, Green & Koschera, 2003; Ho, et al., 2015; Sörensen, Pinquart, & Duberstein, 2002); coping strategies to manage stress (Richardson, Lee, Berg-Weger, & Grossberg, 2013); individualised education through engagement with topics was based on carer goals and needs (Elvish, Lever, Johnstone, Cawley and Keady, 2013); and, blending information with supports such as counselling and motivational components (Elvish, et al., 2013; Pinquart & Sorensen, 2006). The case study therefore also highlights the core need for cross-sectoral partnerships with qualified health professionals, able to bring their specific experience and expertise (e.g. psychologists with dementia experience) to both design and deliver the evidence based programs that were required to support this vulnerable group.

Limitations to the social marketing approach

Despite some successes, the social marketing approach was not useful to support program level improvements. In this study, we did not have control over the actual product (the respite services) and were therefore reliant on the current service system to deliver the proposed benefits. Whilst we sought to support service improvements, workshops with respite providers were insufficient to promote change. Rather, results from this study suggest the persistence of systemic issues associated with the availability, cost, flexibility, and quality of respite services to meet the needs of carers and people with dementia for services at the right time, price, cost, and location (for example see: Phillipson, Jones and Magee 2014). As highlighted by the recent Royal Commission into Aged Care Quality and Safety in Australia (Commonwealth of Australia, 2021), the challenges for delivering high quality services that

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can meet the needs of carers and people with dementia, remain a substantial area in need of practice improvement in aged care. Achieving these system level changes would likely benefit from a wider ecological system approach in addition to the more limited focus of the SM benchmarks on the individual behaviours (Fry et al. 2017), and according to the Royal Commission, substantial changes to the policy and funding mechanism that currently support the aged care system (Commonwealth of Australia, 2021).

Evaluation and impact on aged care and carer policy and practice

Despite some mixed results, evaluation and publication of this aged care social marketing research project has had some impact on aged care policy and practice in Australia, underscoring the potential for social marketing, along with other approaches, to support aged care service improvements. Publications concerning the formative and evaluative research associated with this Case Study were utilised as key evidence in expert witness statements and as part of hearings of the Australian Royal Commission into Aged Care Quality and Safety in 2019 (Royal Commission into Aged Care Quality and Safety 2019). This evidence informed Recommendation 15 to establish a dementia support pathway which includes regular and planned respite for informal carers of people with dementia (Department of Health 2021). Evidence from this social marketing research has also been used to advocate for upstream policy chance. As a result of these efforts, the Australian Government Commonwealth Department of Social Services has applied evidence from the associated research to inform the respite coaching model within the new Integrated Plan for Carer Support Services [Personal Correspondence, 2019].

Conclusion

Overall, the case study highlights the need and potential for community-engaged social marketing to work in partnership with active health supports to improve aged care. However, whilst one without the other, may improve to reach and raise awareness of respite within the

aged caregiver audience, it will not reduce the declines in carer wellbeing that are predictably associated with the intensive role of supporting a person with dementia to live well at home. Both however will face major limitations without a commitment from government to make the systemic improvements that are needed to improve access and availability to quality respite and support services as part of the overall reforms needed to improve the dementia care pathway.

REFERENCES

Andersen, R. (1995), "Revisiting the behavioral model and access to medical care: does it matter?", *Journal of Health and Social Behavior*, Vol. 36 No. 2, pp. 1-10.

Andreasen, A. R. (2002), "Marketing social marketing in the social change marketplace", *Journal of Public Policy & Marketing*, Vol. 21 No. 1, p. 3.

Arksey, H., Jackson, K., Croucher, K., Weatherly, H., Golder, S. and Hare, P. (2004), "Review of respite services and short-term breaks for carers of people with dementia. ", Research Report, London, National Health Service, Service Delivery Organisation.

Australian Institute of Health and Welfare (2007), "Dementia in Australia: National data analysis and development ", Canberra: AIHW.

Baltes, P. B. and Baltes, M. M. (1990), "Psychological perspectives on successful aging: The model of selective optimization with compensation", *Successful aging: perspectives from the behavioral sciences.*, Cambridge University Press, New York, NY, US, pp. 1-34.

Banerjee, S., Murray, J., Foley, B., Atkins, L., Schneider, J. and Mann, A. (2003), "Predictors of institutionalisation in people with dementia", *Journal of Neurology, Neurosurgery AND Psychiatry*, Vol. 74 No. 9, pp. 1315-1316.

Bertrand, R. M., Fredman, L. and Saczynski, J. (2006), "Are all caregivers created equal? Stress in caregivers to adults with and without dementia", *Journal of Aging and Health*, Vol. 18 No. 4, pp. 534-551.

Boustani, M., Perkins, A. J., Monahan, P., Fox, C., Watson, L., Hopkins, J., Fultz, B., Hui, S., Unverzagt, F. W., Callahan, C. M. and Hendrie, H. C. (2008), "Measuring primary care patients' attitudes about dementia screening", *International Journal of Geriatric Psychiatry*, Vol. 23 No. 8, pp. 812-820.

Brodaty, H., Green, A. and Koschera, A. (2003), "Meta-analysis of psychosocial interventions for caregivers of people with dementia", *J Am Geriatr Soc*, Vol. 51 No. 5, pp. 657-64.

Bruen, W. and Howe, A. (2009), "Respite care for people living with dementia: 'it's more than just a short break'", Alzheimer's Australia pp. 1-67.

Carbonneau, H., Carol, C. and Desrosiers, J. (2010), "Development of a conceptual framework of positive aspects of caregiving in dementia", *Dementia and Geriatric Cognitive Disorders*, Vol. 9, pp. 327-353.

Carins, J.E. and Rundle-Thiele, S.R. (2014), "Eating for the better: a social marketing review (2000-2012) ", *Public Health Nutr.*, Vol. 17 No. 7, pp.1628-39.

Commonwealth of Australia (2021), *Royal Commission into Aged Care Quality and Safety, Final report: Care, Dignity and Respect. Volume 1 Summary and Recommendations.* ISBN: 978-1-921091-66-7 (online). Creswell, A. (2017), "Collateral damage: Australian carers' services caught between aged care and disability reforms", *International Journal of Care and Caring*, Vol. 1 No. 2, pp. 275-279.

Department of Health (2021), *Australian Government Response to the Final Report of the Royal Commissions into Aged Care Quality and Safety. Ageing and Aged Care. May 2021.* Recommendation 15: Establishment of a dementia support pathway pp 18-19. Online ISBN: 978-1-76007-435-7. Publications Number: DT0001655

Department of Social Services (2014), "Key directions for the commonwealth home support program discussion paper ", Department of Social Services, available at

http://www.vaccho.org.au/assets/01-RESOURCES/TOPIC-

<u>AREA/POLICY/SUBMISSIONS/Key-Directions-for-the-Commonwealth-Home-Support-</u> <u>Programme-Discussion-Paper-2014.pdf</u>. (Accessed 22nd December, 2021).

Devlin, E., MacAskill, S. and Stead, M. (2007), "'We're still the same people': developing a mass media campaign to raise awareness and challenge the stigma of dementia", *International Journal of Nonprofit and Voluntary Sector Marketing*, Vol. 12 No. 1, pp. 47-58.

Elvish, R., Lever, S.J., Johnstone, J., Cawley, R., and Keady, J. (2013), "Psychological interventions for carers of people with dementia: A systematic review of quantitative and qualitative evidence", *Counselling and Psychotherapy Research*, 13 doi: 10.1080/14733145.2012.739632.

Fielding, E. L., Beattie, E., Readford, M., Neville, C. and Gresham, M. (2012), *Respite care in dementia: consumer perspectives. Final report*, Brisbane, Australia, Dementia Collaborative Research Centre: Carers and Consumers.

Fry, M-L. & Previte, J. and Brennan, L., (2017) "Social change design: disrupting the benchmark template", *Journal of Social Marketing*, Vol.7, pp.119-134.

Fujihira, H., Kubacki, K., Ronto, R., Pang, B. and Rundle-Thiele, S. (2015), "Social marketing physical activity interventions among adults 60 years and older: a systematic review", *Social Marketing Quarterly*, Vol. 21 No. 4, pp. 214-229.

Gaugler, J. E., Kane, R. L., Kane, R. A. and Newcomer, R. (2005), "Early community-based service utilization and its effects on institutionalization in dementia caregiving", *Gerontologist,* Vol. 45 No. 2, pp. 177-185.

Green, J. and South, J. (2006), Evaluation, Open University Press, Maidenhead, Berkshire.

Henderson, J. and Willis, E. (2020) "The marketisation of aged care: The impact of aged care reform in Australia", In: Collyer, F. & Willis, K. (Eds.) *Navigating private and public healthcare: Experiences of patients, doctors and policy-makers*, Singapore, Springer.

Ho, D. W. H., Mak, V., Kwok, T. C. Y., Au, A. and Ho, F. K. Y. (2015) "Development of a web-based training program for dementia caregivers in Hong Kong", *Clinical Gerontologist, Advanced Online Edition*. doi:10.1080/07317115.2015.1008155.

Kuerbis, A., Mulliken, A., Muench, F., Moore, A.A. and Gardner, D. (2017), Older adults and mobile technology: Factors that enhance and inhibit utilization in the context of behavioral health, *Ment Health Addict Res*, Vol. 2, DOI: 10.15761/MHAR.1000136.

Kotler, P. and Lee, N. R. (2008), *Social marketing, influencing behaviours for good*. Sage Publications, Los Angeles.

Mace, N.L. and Rabins, P.V. (2017), *The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer Disease, Other Dementias, and Memory Loss* (6th edition). John Hopkins University Press. ISBN-10 1421422239

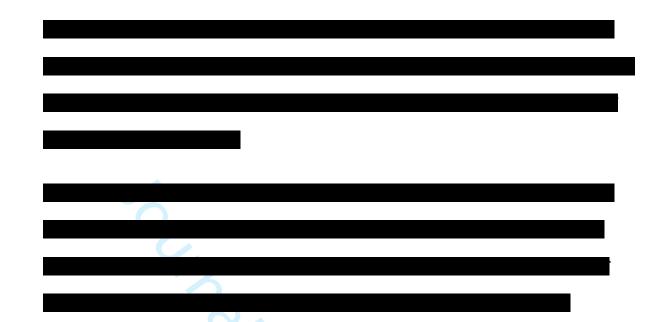
National Institute for Health and Clinical Excellence (2006), "Dementia: a nice-scie guideline on supporting people with dementia and their carers", *National Clinical Guidelines Number 42.*, London, UK, Social Care Institute for Excellence. National Institute for Health and Clinical Excellence.

Neville, C., Beattie, E., Fielding, E. and MacAndrew, M. (2015), "Literature review: use of respite by carers of people with dementia", *Health & Social Care in the Community*, Vol. 23 No. 1, pp. 51-63.

NSMC (2016), *Social marketing benchmark criteria*, England, The National Social Marketing Centre.

Parker, D., Mills, S. and Abbey, J. (2008), "Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review", *International Journal of Evidence Based Healthcare*, Vol. 6 No. 2, pp. 137-72.

Personal Correspondence (2019). Email correspondence between the Carer Reform Team between December 2016 and January 2019 available on request from



Phillipson, L. and Jones, S. C. (2011a), ""Between the devil and the deep blue sea": the beliefs of caregivers of people with dementia regarding the use of in-home respite services", *Home Health Care Services Quarterly*, Vol. 30 No. 2, pp. 43-62.

Phillipson, L. and Jones, S. C. (2011b), "Residential respite care: the caregiver's last resort", *Journal of Gerontological Social Work*, Vol. 54 No. 7, pp. 691-711.

Phillipson, L. and Jones, S. C. (2012), "Use of day centers for respite by help-seeking caregivers of individuals with dementia", *Journal of Gerontology Nursing*, Vol. 38 No. 4, pp. 24-34; quiz 36-7.

Phillipson, L., Jones, S. C. and Magee, C. (2014), "A review of the factors associated with the non-use of respite services by carers of people with dementia: implications for policy and practice", *Health & Social Care in the Community*, Vol. 22 No. 1, pp. 1-12.

Phillipson, L., Low, L.F. and Dreyfus, S. (2019), "Consumer-directed care for older Australians: Are resources identified on the Web adequate to support decisions about homebased care packages?" *Australian Journal of Social Issues*, Vol. 54, pp. 135–156. Pinquart, M. and Sörensen, S. (2006), "Helping caregivers of persons with dementia: which interventions work and how large are their effects? " *Int Psychogeriatr.*, Vol. 18 No. 4, pp. 577-95.

Richardson, T.J., Lee, S.J., Berg-Weger, M. and Grossberg, G.T. (2013), "Caregiver health: health of caregivers of Alzheimer's and other dementia patients", *Curr Psychiatry Rep*. Vol. 15 No. 7, pp. 367.

Royal Commission into Aged Care Quality and Safety (2019). EXHIBIT 7-14

Schmidtke, D.J., Kubacki, K. and Rundle-Thiele, S. (2021), "A review of social marketing interventions in low- and middle-income countries (2010–2019)", *Journal of Social Marketing*, Vol. 11 No. 3, pp. 240-258.

Sörensen, S., Pinquart, M. and Duberstein, P. (2002) "How effective are interventions with caregivers? An updated meta-analysis", *Gerontologist*, Vol. 42 No. 3, pp. 356-72.

Stanziano, S. (2016), "Information seeking behavior of older adults", *The Serials Librarian*, Vol. 71 No. 3–4, pp. 221–30.

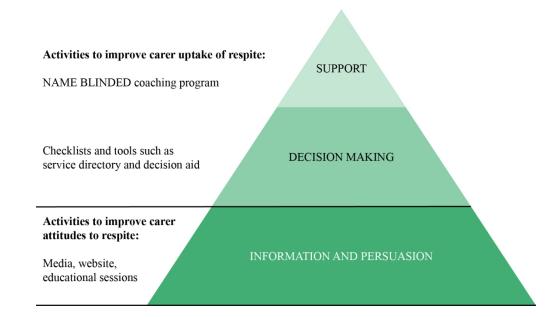
Stead, M., Gordon, R., Angus, K. and McDermott, L. (2007), "A systematic review of social marketing effectiveness", *Health Education*, Vol. 107 No. 2, pp.126-191.

 van Esch, P., Duffy Sarah, M., Teufel, J., Northey, G., Elder, E., Frethey-Bentham, C., Cook Thomas, B. and Heller, J. (2019), "Exerstart: helping seniors be active and independent for less", *Journal of Social Marketing*, Vol. 9 No. 2, pp. 146-160.

Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., Faes, K. and Annemans, L. (2016), "Effectiveness of supporting informal caregivers of people with dementia: a systematic review of randomized and non-randomized controlled trials", *Journal of Alzheimer's Disease*, Vol. 52 No. 3, pp. 929-65.

Windhorst, D. A., Fang, Y., Fierloos, I. N., Crone, M. R., Van Mourik, K. V., Jonkman, H., Hosman, C. M., Jansen, Q. and Raat, H. (2019), "Evaluation of effectiveness of (elements of) parenting support in daily practice of preventive youth health care; design of a naturalistic effect eval-uation in 'CIKEO' (consortium integration knowledge promotion effectiveness of parenting interventions) ", *BMC Public Health*, Vol. 19 No. 1, pp.1462. https://doi.org/10.1186/s1288 9-019-7785-y.

Xia, Y., Deshpande, S. and Bonates, T. (2016), "Effectiveness of Social Marketing Interventions to Promote Physical Activity Among Adults: A Systematic Review", *J Phys Act Health*, Vol. 13 No. 11, pp. 1263-1274.

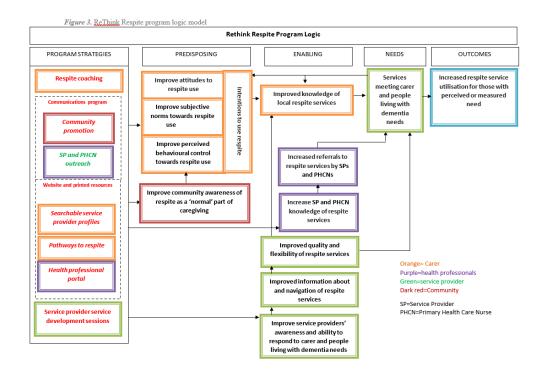


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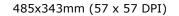


Table I. Stakeholder Consultations

Stakeholder	Participants	Format	Number of
type			consultations
Carer Reference	Former carers (n=5)	Meetings	2
Group			
Service	Dementia Care Service Providers (n=5)	Meetings	3
Reference Group		Interviews	
Dementia service	Day Therapy Centre	Meetings +	19
providers	Regional Dementia Services Networks	telephone	
		consultations	
	Local Health District		
	Local dementia advocacy organisation		
	CRCC		
Online service	Directory providers	Telephone	4
directories		consultations	
Primary care	General Practitioners	Meetings	8
	Primary Care Nurses		
	Primary Care coordinating entities		
Local events	Carers and people living with dementia	Educational	2
		forum	

Researchers	Academics	Telephone consultations	2
		TOTAL	40

Table II. Knowledge, belief and behavioral objectives for target audiences

Target	Awareness objectives	Belief objectives	Behavioral objectives
audience			
Carers and	Respite services are	Quality respite services	Use the NAME
people with	available to meet your	are convenient,	BLINDED website and
dementia	needs	accessible and	other resources
		affordable	Join a carers support
		Respite is a normal part	group
		of the caring process	Plan to use respite
		Respite will benefit you	Enroll in NAME
		and the person with	BLINDED Coaching
		dementia	
		D 111 1	Use respite services
		Respite will help you to	
		care for longer	
		You should plan respite	
		early	
GPs and	Support is available to	NAME BLINDED is a	Refer clients to NAME
primary	help your client find the	credible, useful, local	BLINDED
health care	best service to meet	resource that helps	Use the NAME
	their needs	people with dementia	BLINDED resources
nurses			
nurses		and their carers	including website,

ServiceSupports is available to help your client find the best service to meetNAME BLINDED is a credible, useful, localRefer client BLINDEDbest service to meetresource that helps people with dementiaUse the NA BLINDEDtheir needspeople with dementiaIncluding with including withbelp you improve andNAME BLINDED withdirectory of caching, with	fer clients to NAM
ServiceSupports is available toNAME BLINDED is aRefer clientprovidershelp your client find thecredible, useful, localBLINDEDbest service to meetresource that helpsUse the NAtheir needspeople with dementiaBLINDEDSupport is available toand their carersincluding vhelp you improve andNAME BLINDED willdirectory opromote your servicebenefit my patientscoaching, n	terials fer clients to NAM INDED e the NAME INDED resources luding website, ectory of services ching, marketing
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promote your service benefit my patients coaching, 1	ching, marketing
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lementia	
Identified barriers	Strategies
	Carer education sessions
	Case studies ('Respite Experience' videos)
Perceptions of poor service quality	via website and media releases/stories
	Service provider workshops
	Distribution of services directory
Lack of availability	Promotion of informal respite and lifestyle
	strategies
	Promotion of government subsidized
High monetary cost	services and 'free' strategies such as
	informal respite
	NAME BLINDED coaching
Lack of flexibility in service arrangements	Motivational sessions with service providers
	Cy.
	NAME BLINDED coaching
Expectations that negative outcomes will	Information via education sessions
occur as a result of use	Case studies ('Respite Experience' videos)
	via website and media releases/stories

NAME BLINDED Coaching

Information via education sessions

Case studies ('Respite Experience' videos)

via website and media releases/stories

Decision aids; Checklists to inform service

selection; promoting carer support groups;

Navigating information

Associations with guilt and failure or not

fulfilling family responsibilities

Navigating the aged care system

NAME BLINDED Coaching; improved

promotion of respite services by providers

Decision aids; Checklists to inform service

selection; promoting carer support groups;

Jarren 20

NAME BLINDED Coaching