Invisible Patients:

Attending to Dementia’s Burden on Caregivers by way of Social Marketing

Dementia is a burdensome condition, for both those afflicted by it and those caring for them. Over one million Australians’ lives are presently impacted by dementia;¹ this number will increase in tandem with the prevalence of dementia as Australia’s population ages.² While burden alleviation is available for caregivers of individuals with dementia through respite care, such means are not utilised to their potential.³ This arises through a complex interplay of motivations and perceived barriers of both members of the caregiver-care recipient dyad.⁴ This paper maintains a dyadic perspective in proposing a social marketing campaign promoting increased utilisation of respite care by individuals caring for others with dementia. With the delay of institutionalisation recommended for treatment of individuals with dementia⁵ and often sought by both members of the dyad,⁶ minimisation of caregivers’ burden is paramount.

Dementia is an umbrella term referring to a condition characterised by impaired cognitive functioning and associated with many different diseases.⁷ Manifestations include diminished reasoning ability, behavioural disinhibition, memory impairments and depression.⁸ While the

⁷ Australian Government, Dementia in Australia.
⁸ ibid.
symptoms themselves, their severities and their development vary, dementia is typically of gradual onset, progressive, and irreversible, leading to complete dependence and ultimately, death. Alzheimers disease is the most common form of dementia, accounting for approximately 70% of Australian cases. Dementia is not a natural process, despite its prevalence increasing with age, and early symptoms can be incorrectly associated with aging or stress. Given its idiopathic nature, there is presently no cure for the disease. These notions, alongside Australia’s aging population, foreshadow an increase in the number of cases and relative prevalence of dementia in Australia alike. (See Appendix) In turn, this predicts greater numbers of caregivers in need of respite.

Currently, over one million Australians’ lives are impacted by dementia, either afflicted by it themselves or caring for someone who is. While caregivers’ roles may impact their lives physically, economically, socially or psychologically, many do not seek to alleviate their own burden through available means, such as respite care. This occurs despite many caregivers being spouses or children of the individual with dementia, who often lack explicit training regarding such provision of

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9 Australian Government, Dementia in Australia.  
10 Alzheimer’s Australia, Dementia is Everybody’s Business.  
11 Dementia is typically associated with people aged over 65; younger onset dementia refers to people below this age experiencing dementia. (Australian Government, Dementia in Australia.) The two will not be differentiated in this paper, as both categories burden caregivers.  
14 While many risk and protective factors have been correlative identified, few have been definitively established. (Seeher et al., The Dementia Research Mapping Project.)  
15 Australian Government, op. cit.  
16 ibid.  
17 Alzheimer’s Australia, Fight Dementia Campaign.  
19 Alzheimer’s Australia, Dementia is Everybody’s Business.
care.\textsuperscript{20} This arises from a complex interplay of behaviours by both members of the caregiver-care recipient dyad.\textsuperscript{21}

Many individuals with dementia are reluctant to admit their need for assistance.\textsuperscript{22} Furthermore, those afflicted are widely stigmatised; 22\% of Australians report feeling uncomfortable spending time with someone suffering from dementia,\textsuperscript{23} and 60\% anticipate experiencing feelings of shame if diagnosed with dementia.\textsuperscript{24} In tandem, these factors encourage dissociating oneself from the condition. This contributes significantly to preliminary professional consultations regarding the diagnoses of new cases occurring, on average, three years after symptoms are first noticed,\textsuperscript{25} thereby resulting in under-utilisation of available support and the underestimation of dementia’s prevalence.\textsuperscript{26} 16\% of Australians report knowing someone who might have dementia but has sought neither diagnosis nor treatment; this rises to 41\% among caregivers.\textsuperscript{27} Delaying treatment worsens symptoms, predicts higher health care utilisation, and exacerbates the burden borne by caregivers.\textsuperscript{28}

Caregivers themselves bear their own barriers to seeking alleviation of their burden, which largely arise through a sense of duty.\textsuperscript{29} In tandem, this sense of duty and desire for respite can result in cognitive dissonance, discomfort arising from simultaneously holding contradictory attitudes.\textsuperscript{30} Respite care is consequently under-utilised in an effort to resolve this internal conflict.\textsuperscript{31} In addition, caregivers cite concerns about the quality and flexibility of respite services presently available.\textsuperscript{32}

\textsuperscript{21} Judge et al., “Improved Strain and Psychosocial Outcomes for Caregivers of Individuals with Dementia: Findings from Project ANSWERS”.
\textsuperscript{23} Alzheimer’s Australia, \textit{Dementia is Everybody’s Business}.
\textsuperscript{24} Alzheimer’s Australia, \textit{Fight Dementia Campaign}.
\textsuperscript{26} Australian Government, \textit{Dementia in Australia}.
\textsuperscript{27} Alzheimer’s Australia, \textit{Dementia is Everybody’s Business}.
\textsuperscript{28} Laura N Gitlin, “Good News for Dementia Care: Caregiver Interventions Reduce Behavioral Symptoms in People with Dementia and Family Distress,” \textit{American Journal of Psychiatry}, 169, no. 9 (2012): 894-897.
\textsuperscript{29} Brodaty and Donkin, “Family Caregivers of People with Dementia.”
\textsuperscript{31} Alzheimer’s Australia, \textit{Dementia is Everybody’s Business}.
\textsuperscript{32} \textit{Ibid.}
Consequently, many caregivers are reluctant to permit themselves to utilise respite, particularly in light of their most readily accessible referent; there can be an underlying sentiment of “they have it worse than me”.33 This decisional conflict has been linked to poor health outcomes for caregivers and earlier institutionalisation of care recipients.34 Furthermore, given the condition’s gradual onset, caregivers may similarly acclimatise to their increased burdens, ignorant of the extent to which their lives are impacted.35 Indeed, perceived strain is only somewhat correlated with objective burden.36

The needs of the dyad’s constituents may differ, and indeed, interventions looking to address the negative outcomes associated with dementia often target the caregiver and care recipient separately.3738 While differences between the caregiver and care recipient’s experience of dementia give credence to separate approaches, interventions founded upon this notion may fail to capture the nature of everyday interaction that occurs within the dyad.39 Thus, opportunities for insights subsequently prompting a more effective interaction between the dyad’s members are inherently limited.40 Numerous studies have shown dyadic interventions to be effective thus far.414243 These will hence play a significant role in alleviating the burden borne by increasing

33 Brodaty and Donkin, “Family Caregivers of People with Dementia.”
34 ibid.
35 ibid.
39 Judge et al., “Improved Strain and Psychosocial Outcomes for Caregivers of Individuals with Dementia: Findings from Project ANSWERS”.
40 ibid.
41 ibid.
numbers of caregivers as dementia becomes more prevalent among Australia’s aging population and be integral to the proposed social marketing campaign.

A suitable framework through which to offer a solution to dementia’s burden on caregivers, augmented by caregivers’ own reluctance to acknowledge their burden, is Ansoff’s growth strategy of market development through Porter’s generic strategy of focussed differentiation. In pursuing market development, growth is sought through targeting new market segments with existing products or, as in this instance, behaviours. A strategy centring on focussed differentiation targets a narrow segment of the market in seeking to differentiate one’s offering from others. Again, this hereby constitutes encouraging one behaviour as opposed to another.

In presenting a social marketing solution to the under-utilisation of respite care by caregivers of individuals with dementia, there are three barriers which the solution must overcome or bypass:

- The shame widely associated with being afflicted by dementia
- The guilt experienced by caregivers in considering the use of respite care
- Caregivers’ concerns about the quality of the respite services available

A media campaign targeting caregivers of individuals with dementia stressing the dyadic benefits of employing respite care through personal information sessions presents a plausible social marketing solution. In accordance with the aforementioned theoretical framework, this approach is largely differentiated from existing ones in targeting one dyad member as a channel to benefit both

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44 Australian Government, *Dementia in Australia*.


47 Ansoff, op. cit.

48 Porter, op. cit.

49 Alzheimer’s Australia, *Fight Dementia Campaign*.

50 Brodaty and Donkin, “Family Caregivers of People with Dementia.”

51 Alzheimer’s Australia, *Dementia is Everybody’s Business*. 
members simultaneously, and narrow in targeting only a segment of the market, as discussed later in the paper. The behaviour is existing in that respite care is presently available, and the market new in that the campaign would be aimed at those not presently demonstrating the behaviour of utilising it. Furthermore, the solution offers an answer for each of the three aforementioned barriers.

While targeting the caregiver rather than the care recipient circumvents the first barrier, it is consequently dependent on overcoming the second. In light of the guilt caregivers experience in considering utilising respite care, the campaign will appraise the situation from a dyadic perspective and stress the benefits for both members. That is, in targeting the caregiver, the campaign will emphasise how the care recipient benefits from the caregiver’s own respite, such as delayed institutionalisation. Finally, providing face-to-face information sessions with staff involved in local respite care services personalises the experience. It offers provision of more in-depth and case-specific information and greater familiarisation with those involved than could be provided through mass communication means such as a website. Information delivered via telephone, by the National Dementia Helpline, could meet the first, but not the second, of these conditions.

This solution’s dyadic nature is evident in that it addresses the dyad’s members’ respective barriers simultaneously. Caregivers’ guilt is assuaged by the long-term benefits of their actions for the care recipient, while the latter’s shame is moderated through the experience’s personalisation. Social comparison theory posits that people evaluate themselves relative to those around them.

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52 Olzarán et al., “Nonpharmacological Therapies in Alzheimer’s Disease: A Systematic Review of Efficacy.”
However, referents to whom an individual is close, such as friends and family, mediate this evaluative process through familiarity.\textsuperscript{55}

This solution can be delivered as a market-based offering through the adaptation and adoption of the Chartered Institute of Marketing approach to marketing, which defines marketing as “the management process responsible for identifying, anticipating and satisfying customer requirements profitably.”\textsuperscript{56} Akin to the methodology of matching benefits to barriers employed earlier, the components of the definition can be matched to those of the solution. The customer parallels the caregiver, who must be persuaded to acknowledge their own limitations and the benefits of respite. Profit denotes the benefits the caregiver can obtain through utilising respite care; there exist direct and indirect benefits alike. The former refers to the lessening of the burden borne, and the latter encapsulates the care recipient’s benefit of delayed institutionalisation,\textsuperscript{57} thereby further benefitting the caregiver themselves through reducing their barrier of guilt. Caregivers’ requirements have been identified in that respite services are already available. However, barriers and their resultant impact upon consumer behaviour thus far have been poorly anticipated, resulting in the under-utilisation of the service. Consequently, caregiver needs are not presently being satisfied.

Here, the notion of profitability employs the existing behaviour, caregivers’ abstention from respite, as a referent. Caregivers derive some form of benefit, alleviation of guilt, from not utilising respite care, and must hence be persuaded that this does not yield the best possible outcome. Caring for an individual with dementia allows the caregiver to avoid feelings of guilt associated with offloading their responsibility derived from a sense of duty and perceived obligation to care for the individual.\textsuperscript{58} Thus, the solution must be conceived of by caregivers as being of greater benefit to the

\textsuperscript{57} Olzarán et al., “Nonpharmacological Therapies in Alzheimer’s Disease: A Systematic Review of Efficacy.”
\textsuperscript{58} Brodaty and Donkin, “Family Caregivers of People with Dementia.”
care recipient than the caregiver’s own current behaviour. This emphasises the dyadic perspective once more, in that behaviours benefitting the caregiver themselves will also benefit the care recipient.

The relevant market can be segmented along two dimensions. The first is the role assumed in the caregiver-care recipient dyad by the consumer; the second is the stage of Prochaska and Diclemente’s transtheoretical model of behaviour change\(^59\) (TTM) presently occupied by the consumer.

In appraisal of the first dimension, the two individuals involved in the dyad present different barriers to be overcome and offer different opportunities in pursuit of a successful social marketing campaign. Caregivers’ main barriers are their sense of duty and the guilt subsequently evoked by the notion of utilising respite care,\(^60\) while the opportunity presented is their more objective perception of the impact dementia is having on the care recipient’s life.\(^61\) Care recipients’ principal barrier is the shame arising through their simultaneous reluctance to acknowledge their condition in accordance with their valuing of independence.\(^62\) Nonetheless, they too present an opportunity, in that demonstrating initiative and confronting the difficulties they face could be conceptually aligned with independence. It should be noted that this opportunity is dependent upon the care recipient themselves being in the early stages of disease, such that they can appraise and interact with the world around them, as these abilities erode with the worsening of the recipient’s condition.\(^63\)

Regarding the second, the TTM posits that there are five constituent stages of behaviour change through which people progress; progressively, these are pre-contemplation, contemplation, preparation, action and maintenance.\(^64\) Pre-contemplation constitutes a lack of acknowledgement

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\(^{60}\) Brodaty and Donkin, “Family Caregivers of People with Dementia.”

\(^{61}\) Alzheimer’s Australia, *Dementia is Everybody’s Business*.

\(^{62}\) McCrindle, *The ABC of XYZ*.

\(^{63}\) Australian Government, *Dementia in Australia*.

\(^{64}\) Prochaska and DiClemente, *op. cit.*
that a problem exists and consequently that a change is required. Contemplation invokes the recognition that a problem exists, while preparation involves making plans for change. Action involves the first actual attempt to modify a problematic behaviour, which must subsequently be maintained for a period of time. While not considered a stage itself per se, relapse constitutes regressing from one stage to an earlier one.

As the two individuals involved in a given dyad may be at different stages of behaviour change, there exists an array of segments which could be targeted by this social marketing campaign. Pre-contemplative individuals with dementia and caregivers alike do not believe that they themselves require assistance. The distinction between these two is the caregiver’s acknowledgement of the impact dementia is having upon the care recipient’s life. Caregivers in contemplation are likely concerned with their own quality of life, while corresponding care recipients are beginning to acknowledge their requirement for care. Caregivers and care recipients in the preparation stage both require access to information and must perceive there to be an opportunity for the behaviour of interest, respite care, to occur and offer the benefits sought by each. In pursuit of market development,65 individuals in either the action or maintenance stages would not be targeted under this campaign, as they are already demonstrating the behaviour of interest. Due to the potential for disparity between the stages of behaviour change presently occupied by each of a given dyad’s constituents, while the campaign would emphasise dyadic benefits, it would target only one member.

Thus far, campaigns have typically targeted care recipients.666768 In emphasising differentiation, this campaign will target caregivers. This is logical from a barrier-centric perspective, in that caregivers deny they need help with a problem, whereas care recipients may deny that there

65 Ansoff, “A Model for Diversification.”
67 Alzheimer’s Australia, Fight Dementia Campaign.
68 Alzheimer’s Australia, Dementia is Everybody’s Business.
is a problem altogether. In light of delayed treatment of the care recipient exacerbating the burden fronted by caregivers, the campaign will target caregivers in the contemplation stage of the TTM; this would constitute the single market segment to be targeted mentioned earlier.

This target market will be more receptive than those in pre-contemplation, and the transmission between contemplation and preparation will be quickened. This is arguably the most significant bridging after that between pre-contemplation and contemplation, in that if the barriers impeding the issue’s resolution are perceived to be too complex to confront, it is unlikely to be resolved. Furthermore, cognitive dissonance is most likely to occur at this stage. The dyadic perspective is integral to reconciling the conflicting attitudes. Furthermore, the conceptualisation of respite care as benefitting the dyad must be internalised, thereby eliciting true attitude change. This is enabled through emphasising the benefits of the caregiver’s respite for the care recipient. Caregivers’ ignorance of the impact upon their lives arises through excessive self-efficacy, whereby they believe they are more capable of handling the burden than they truly are, and are thus less likely to pursue respite. Caregivers in the contemplation stage of the TTM thus exhibit maximal receptiveness to internalisation of the idea that respite care can benefit the dyad in that they are presently acknowledging their own burden, but have had minimal time to acclimatise to it.

Despite dementia’s burden on caregivers, available respite care services are under-utilised, due largely to barriers of guilt and the interdependent nature of the caregiver-care-recipient dyad. A plausible means by which to increase utilisation of respite services is the promotion of the behaviour through a media campaign targeting contemplative caregivers of individuals with dementia emphasising the dyadic benefits of employing respite care through personal information sessions. In pursuit of maximal effectiveness, the campaign should target caregivers presently in the

69 Gitlin, “Good News for Dementia Care: Caregiver Interventions Reduce Behavioral Symptoms in People with Dementia and Family Distress.”
71 Campbell et al., “Determinants of Burden in Those Who Care for Someone with Dementia.”
contemplation stage of Prochaska and DiClemente’s TTM,\textsuperscript{73} likely to offer peak receptiveness to internalisation of a new attitude in an effort to resolve their current state of cognitive dissonance before acclimatisation to their burden prompts excessive self-efficacy. This campaign should be delivered through a framework of marketing theory centring on Ansoff’s growth strategy of market development,\textsuperscript{74} targeting caregivers not presently utilising respite care. Furthermore, it should employ Porter’s generic strategy of focussed differentiation,\textsuperscript{75} targeting only those deemed most receptive. Amid Australia’s aging population,\textsuperscript{76} effective resolution of this situation is paramount; 7\% of Australians presently care for an individual with dementia; 64\% believe they will likely do so in the future.\textsuperscript{77}

\textsuperscript{73} Prochaska and DiClemente, “Transtheoretical Therapy: Toward a More Integrative Model of Change.”
\textsuperscript{74} Ansoff, “A Model for Diversification.”
\textsuperscript{75} Porter, \textit{Competitive Strategy: Techniques for Analyzing Industries and Competitors}.
\textsuperscript{76} Australian Government, \textit{Dementia in Australia}.
\textsuperscript{77} Alzheimer’s Australia. \textit{Dementia is Everybody’s Business}.
Appendix: Forecast of Dementia in Australia

Figure 1: Projections of Australia’s population of people aged over 65 until 2050.\(^{78}\)

Figure 2: Projections of cases of dementia in Australia until 2050.\(^{79}\)

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\(^{78}\) Australian Government, *Dementia in Australia.*

\(^{79}\) *Ibid.*
References


