



Case Study Evaluation: Past, Present and Future Challenges

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THE CASE FOR EVALUATING PROCESS AND WORTH: EVALUATION OF A PROGRAMME FOR CARERS AND PEOPLE WITH DEMENTIA

Samantha Abbato

ABSTRACT

A case study methodology was applied as a major component of a mixed-methods approach to the evaluation of a mobile dementia education and support service in the Bega Valley Shire, New South Wales, Australia. In-depth interviews with people with dementia (PWD), their carers, programme staff, family members and service providers and document analysis including analysis of client case notes and client database were used.

The strengths of the case study approach included: (i) simultaneous evaluation of programme process and worth, (ii) eliciting the theory of change and addressing the problem of attribution, (iii) demonstrating the impact of the programme on earlier steps identified along the causal pathway (iv) understanding the complexity of confounding factors,

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(v) eliciting the critical role of the social, cultural and political context, (vi) understanding the importance of influences contributing to differences in programme impact for different participants and (vii) providing insight into how programme participants experience the value of the programme including unintended benefits.

The broader case of the collective experience of dementia and as part of this experience, the impact of a mobile programme of support and education, in a predominately rural area grew from the investigation of the programme experience of 'individual cases' of carers and PWD. Investigation of living conditions, relationships, service interactions through observation and increased depth of interviews with service providers and family members would have provided valuable perspectives and thicker description of the case for increased understanding of the case and strength of the evaluation.

Keywords: Case study; evaluation; mixed methods; dementia; public health

EDITORS' INTRODUCTION

Too many evaluations of medical programmes take a 'black box' approach, measuring both inputs and predefined outputs but paying little or no attention to the intervening processes or mechanisms. In this chapter, Sam Abbato describes how she used case study methodology as a major component of a mixed-methods approach to the evaluation of a mobile dementia education and support service in New South Wales, Australia. Her dataset included in-depth face-to-face interviews with people with dementia (PWD), their carers and programme staff, phone interviews with family members and service providers and analysis of documents including client case notes. She found that the construction of a in-depth case study allowed her to go beyond the 'black box' approach in a number of ways: she could evaluate simultaneously the programme's processes and its worth; elicit a complex theory of change and address the problem of attribution; demonstrate the impact of the programme on earlier steps identified along the causal pathway; understand the complexity of confounding factors; elicit the critical role of the programme's social, cultural and political context; understand why the programme had different impact for different participants; and provide insights into how programme participants experienced its value (including unintended benefits). The author reflects that had she been able to gather more data from front-line users and providers of

the service, her description would have been even ‘thicker’ and included a wider variety of perspectives.

INTRODUCTION

The focus of much evaluation is on whether the programme meets its goals. Evaluations with a strong quantitative grounding based on a positivist epistemology continue to hold a higher status than context-rich approaches that take into account social conditions and the lived experience of programme participants (Boruch & Foley, 2000; Campbell et al., 2000, 2007; Moher, Schulz, & Altman, 2001; Pawson & Tilley, 1997; Victoria, Habicht, & Bryce, 2004). Part of the reason for this persistent imbalance in public health is the continued focus of researchers on diseases and risk factors (Syme, 2004). Trials of new medicines and preventive agents have influenced the principles on which public health interventions are based and therefore evaluated (Victoria et al., 2004). The limitations of quantitative evaluation methods, including the espoused gold standard randomised controlled trial, are increasingly acknowledged in the public health and evaluation literature (Cook, Scriven, Coryn, & Evergreen, 2010; Radio National Health Report, 2014; Scriven, 2008; Victoria et al., 2004). However, application of case study methodologies to address the complexity of many public health evaluations appears to be a conceptual and practical leap few public health academics and evaluators are prepared to contemplate, choosing instead to ‘add on’ select qualitative methods to an overall quantitative evaluation design in an effort to somehow account for the complexity of programmes in context (Campbell et al., 2000, 2007).

This chapter is written from the perspective of an evaluation practitioner with academic grounding in the theory and methods of both public health epidemiology and medical anthropology and a pragmatic mixed-methods approach to evaluation practice (Howe, 1988; Johnson & Onwuegbuzie, 2004). Through the experience of applied evaluation work for clients in the public health sector, I discuss the limitations of evaluation dominated by quantitative methods and the strengths of the application of case study to address these limitations as both a ‘stand alone’ and combined mixed-method approach.

The qualitative case study was developed to ‘study the experience of real cases operating in real situations’ (Stake, 2006). This approach is

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particularly advantageous when the boundaries between the phenomena of interest and the contextual conditions are not clearly evident (Yin, 2014). To demonstrate the strengths of the case study approach to public health evaluation practice, I present an example of the evaluation of a mobile intervention to support carers and people living with dementia in a rural area of New South Wales, Australia.

The documented limitations of a positivist goal-based approach to evaluation include: (a) inability to document complexity and account for the impact of contextual factors (Campbell et al., 2007), (b) lack of evidence of the causal pathway by which the programme works (Patton, 1998), (c) deficiency in identifying emerging programme goals and objectives and unintended programme benefits (Scriven, 1993), (d) lack of information about programme processes for programme improvement and potential adaptation to other settings (Yin, 2014), and (e) limited understanding of how various groups including participants and stakeholders value the programme (Mertens, 2007).

Consideration of context has been acknowledged as crucial when interpreting quantitative evaluation findings and assessing whether a public health intervention that was successful in one setting might work in others (Campbell et al., 2007). However, add-on methods to randomised controlled trials of complex interventions, such as the use of work diaries and parallel qualitative studies, have shown limited success in illuminating the complexity of contexts in which interventions occur (Campbell et al., 2007). Understanding how things work under different local conditions and being able to account for contextual factors that interact and influence participants and programme outcomes, including those of time and place, are major strengths of the case study method – where evaluation includes interpreting programme effects in context and observing these in natural social conditions (Cronbach, 1975; Simons, 2009; Yin, 2014).

The ‘black box’ is a term that has been commonly used in public health research, epidemiology and evaluation to relate a putative causal factor to an observed effect without knowing the mechanisms that contributed to the transformation from intervention to observed change (Last, 1988). Patton alternately uses the terms empty box, magic box or mystery box to describe evaluations that analyse what goes in and comes out without information about how things are processed in-between (Patton, 1998). Quantitative evaluation that reduces a programme to input and activity variables and outputs and outcomes, for example, those that involve pre and post testing, lack information about what actually happened to

participants between tests and how they experienced the intended intervention and what the causal mechanisms were (Funnell & Rogers, 2011; Patton, 2012). The lack of attention to qualitative evidence in quantitative evaluation work and that science depends upon qualitative, good sense knowing, have long been noted (Campbell, 1975; Simons, 2009). Qualitative methodologies and mixed methods including qualitative case studies provide important strategies for inferring causation in evaluation, including the identification of the underlying causal mechanism (Davidson, 2005). Furthermore, public health programmes designed to facilitate behaviour modification or improvement in 'quality of life' operate in complex social and cultural contexts and evaluations are often restricted by relatively short time frames that are unlikely to detect changes sought through quantitative indicators. In contrast, the case study approach can explain causal links and detect early shifts in real life interventions that are too complex for survey or experimental strategies (Yin, 2014).

Goal achievement evaluation, which is commonly a feature of a quantitative approach, can miss many aspects of a programme that are key to its value, including unintended consequences (Scriven, 1993). In addition, quantitative approaches to evaluation often exclude the participant voice and programme perspective (Mertens, 2007). The case study approach to evaluation enables flexibility and the opportunity to identify programme goals that have evolved over time and that are of value to programme recipients and other stakeholders (Simons, 2009).

Compared to the published literature on outcome evaluation of public health programmes, there are few studies that document public health intervention successes or failure and there has been a call for an increased focus on process evaluation for advancing the understanding of interventions (Linnan & Steckler, 2002). One of the potential limiting factors in progressing process evaluation is the view expressed by distinguished evaluators and social scientists that an evaluation should focus on either process evaluation or summative evaluation, but never both. For example Patton quotes Donald Campbell, 'Evaluate no programme until it is proud' (Patton, 2012).

The case study approach can generate an in-depth picture of how a programme is experienced by participants and as such provides rich information on how the programme operates and sequence of events, enabling simultaneous evaluation of processes and determination of programme value (Stake, 2006). Indeed, it is near impossible to separate process and summative evaluation through the application of case study methodology to evaluation.

Voices of participants are not a focus of the objectivism that underpins quantitative approaches to evaluation. For example, pre and post programme measurements of social phenomena and the categories used for measurement are assumed to exist independently of the programme participants (Bryman, 2004). A strength of the case study approach is that it can give voice to programme participants and communities and respond to their needs (Mertens, 2007; Simons, 2009). Furthermore, the documentation of programme experience from the participant voice provides stories that have power to enable audiences of the evaluation report to vicariously experience what was observed by the evaluation team (Simons, 2009). Narratives that create emotion are quickly and easily stored in the brain of the reader or listener and have power in being able to connect with the story recipient's previous knowledge and experience (Wilson, 2002).

A case study methodology was applied as a major component of a mixed-methods approach to the evaluation of the Mobile Respite Team (MRT) service in the Bega Valley Shire, New South Wales, Australia. The MRT programme and case study evaluation approach are described below. The evaluation findings and the strengths and limitations of the case study approach are discussed and compared to quantitative evaluation strategies applied to the evaluation of similar programmes. Lessons learned from the perspective of an applied evaluation practitioner are highlighted.

The Mobile Respite Team Service, Bega Valley Shire

In the early 1980s in Australia, state and territory Alzheimer's Associations were established as self-help organisations by and for family carers of people with Alzheimer's disease and other dementias. Alzheimer's Australia has rural and regional services in each state and territory providing local support to people living with dementia, their families and carers. The MRT service is a programme of the Bega Valley Shire Alzheimer's Australia service in New South Wales. It is funded by the Department of Social Services under the National Respite for Carers Programme (NRCP).

The MRT service provides assistance to PWD and their carers across the Bega Valley Shire local government area located on the south-eastern coastline of New South Wales. The Bega Valley Shire covers an area of 6,279 square kilometres, sparsely populated by approximately 31,950 people (Australian Bureau of Statistics, 2013). The MRT service includes two

team members who respond quickly with education, support and respite for both the carer and PWD in their own home across the region.

Alzheimer's Australia offers two other mobile respite services that commenced at around the same time, approximately 10 years ago, in different locations in Australia, Western Australia and the Australian Capital Territory. These other programmes have evolved very differently from MRT (Bega Valley Shire), resulting in MRT being a unique programme of assistance to carers and PWD.

At the time an external evaluation of MRT was sought in January 2013, the programme had never been evaluated or formally documented. The impetus for evaluation was to formally identify and document the MRT programme model, and determine its value to PWD, their families and carers to inform a decision on continuation of the programme and its extension to other regions ([Aged Care Reform Implementation Council, 2013](#); [Howe, Blake, & Rees, 2013](#)). MRT staff were aware that the programme had evolved over 10 years to cover more than respite and education for the carer and that it was considered to be of great value to both clients and local service providers.

EVALUATION APPROACH

The evaluation was developed through consultation with MRT management and programme staff and designed to address two key evaluation questions, one with a focus on process and one on outcome or summative evaluation:

- (i) What is the operational model of MRT and its future applicability locally and to other regions of Australia?
- (ii) What is the value of MRT to PWD, their families, carers, the aged care sector and the community?

Budget and time constraints were a major consideration in the development of the evaluation methodology. The evaluation report was required twelve months from commencement, six months before the end of the programme's current funding under NRCP. The budget and time constraints limited the period of data collection to nine months (March–November 2013) and on-site fieldwork to five days, which was completed by two evaluators skilled in qualitative research methods working together.

A mixed-methods evaluation approach was used. The quantitative component included a pre and post survey administered to carers and the PWD at commencement of the service and at the eighth visit by the MRT and a survey administered at exit from the service. This included measurement of change in carer and PWD quality of life (QoL) resulting from participation in the MRT service based on use of established QoL instruments – the Adult Carer Quality of Life Questionnaire (AC-QoL) (Elwick, Joseph, Becker, & Becker, 2010) and the Quality of Life – Alzheimer’s Disease (QoL – AD) (Logsdon, Gibbons, McCurry, & Teri, 1999, 2002). The quantitative methodology is described in more detail elsewhere (Abbato, 2014).

The qualitative component included: in-depth face-to-face interviews with PWD, their carer’s and MRT staff, phone interviews with family members and service providers and document analysis including analysis of client case notes and client database. The qualitative elements (major component) were combined with quantitative analysis of the client database (minor component) to develop a single explanatory case study of the MRT service, Bega Valley Shire.

Qualitative Component – Development of the Case Study

Participants at various stages of involvement in the MRT service, representing different types of carer–PWD relationships (e.g. parent/adult child, husband/wife), different genders, different types of broader family situations (e.g. second marriages as well as first, supportive and unsupportive families) were selected to represent a diverse range of client types. Interviews were conducted in participants’ homes in early June 2013 by the external evaluator. The interview team (interviewer and note-taker) were introduced to participants by the MRT staff and once a level of rapport was established, the MRT staff occupied either the carer or PWD with an activity.

Interviews were face-to-face, semi-structured (in conversational style, aided by a topic guide) and lasted approximately 90 minutes (carers) and 30 minutes (PWD). The carer interview schedule included questions on: (i) initial contact with MRT, why they needed it, how they knew of it and what made them start with the service, (ii) what sorts of things they learnt about dementia from the MRT, (iii) what difference MRT made to their relationship with the person they are caring for, including management of behaviours, (iv) what difference MRT made to their relationship with other family members, (v) access to community support, respite services and

other service providers, (vi) changes in quality of life and (vii) suggested improvements for MRT.

The PWD interview guide included broad open-ended questions on: (1) good things about the service, (2) how the service has helped them, (3) what difference the service has made to their life and (4) how different their life would be without the service. A third party approach was used to elicit more information from PWD as suggested by the literature (Aggarwal et al., 2003; Allan, 2000). For example, PWD were asked, 'What would you say about (*MRT workers names*) and what they did for you, if a friend asked you 'How they helped?' If a friend's name was known through the interview with carer, the specific name of the friend was used in this sentence. Other specific prompts based on what the activities the MRT workers and PWD had recently done together as part of the service were used where possible. Photos of the MRT workers were used as a memory aid for PWD.

To increase the validity of the qualitative data, triangulation of: interviewer, perspective, data source and method were used (Denzin, 1978; Patton, 1987). Interviewer and note-taker discussed their interpretations after the interview. Triangulation of data source was used by comparing interview notes with MRT case notes and quantitative data from the MRT client database and pre and post surveys.

A total of 10 client sets participated in in-depth interviews. This included 10 carers of PWD (three wives, five husbands, two daughters), four PWD (the others were in residential care or not well enough to be interviewed), two family members (both daughters) living some distance away but closely involved with the carer and PWD and in regular contact with MRT (interviewed by phone), six stakeholders involved in providing services to several of the clients and the two MRT workers (interviewed by phone after preliminary analysis of the data on other participants).

Stakeholder interviews lasted approximately 30 minutes and followed a semi-structured question guide for each of the clients they were familiar with. Questions included: (1) most important things MRT did to assist client, (2) how the client journey would be different without MRT and (3) whether the client could get this assistance from another source. Questions were also asked about each of the major themes of the MRT model arising from the in-depth interviews with carers, PWD and family members.

Qualitative thematic and content analysis were used to analyse data and develop the explanatory case study. To protect confidentiality, four composite client stories were developed, each based on a combination of two to

three actual client stories. The individual stories were central to: (i) understanding the programme and its value through the perspective of the PWD, carers and families experiencing it, (ii) documenting the ‘lived experience’ of the programme and (iii) interpreting the impact of social, cultural and political factors on the clients (Simons, 2009).

THE ROLE OF THE CASE STUDY IN DETERMINING PROGRAMME VALUE

Limitations of Quantitative Method of Determining Change in Quality of Life

Consistent with the literature, the quantitative methodology employed in the evaluation was a pre and post-test design using a main outcome measure, in this case carer and PWD QoL, and a follow-up point of an average of six months (Brodaty, Green, & Koschera, 2003; Pinquart & Sorensen, 2006). The specific quantitative findings are reported elsewhere (Abbato, 2014). In summary, the pre and post survey failed to show any overall improvement in QoL of either the carer or PWD from the first to the eighth visit by MRT. One of eight subscales in carer quality of life, ‘Ability to care’ (defined as the extent to which the carer is able to provide care for the person they care for, how they cope with the caring role and how they feel about their competency to care) showed significant improvement over the first eight MRT visits ($P=0.036$, Wilcoxon Signed Ranks). The MRT workers noted that administration of the AC-QoL provided useful practical information and they were able to use it as a diagnostic tool to assist in increasing their understanding of the areas of carer life requiring increased support and in informing the tailored intervention for the individual carers.

The quantitative component of this evaluation was limited by a small sample size of seven carer/PWD pairs. However, major limitations on the quantitative pre/post design cannot be resolved through either increase in sample size, controlling for confounding variables, or the addition of a ‘control group’ and randomisation (Patton, 2008; Syme, 2004; Thompson & Gifford, 2000). These strategies of (alleged) methodological improvement (Brodaty et al., 2003) fail to ‘open the black box’ and answer the ‘why’ question, critical to eliciting a rich understanding of how the intervention works and enabling an contextualised understanding of the challenges and potentialities of the intervention (Bourguignon & Sundberg, 2007; Greene,

2004, p. 175; Greenhalgh, Macfarlane, Barton-Sweeney, & Woodard, 2012; Patton, 2008, p. 449).

The Strengths of the MRT Programme Evaluation Case Study

The strengths of the case study applied to the evaluation of the MRT programme include: (i) simultaneous evaluation of program process and worth, (ii) eliciting complexity of the theory of change and addressing the problem of attribution, (iii) demonstrating the impact of the programme on earlier steps identified along the causal pathway that were not measured quantitatively, (iv) understanding ‘confounding factors’ affecting programme impacts were not separable but intertwined with the programme activities and quantitative measures of outcomes, (v) eliciting the critical role of social, cultural and political context, (vi) understanding the importance of influences contributing to differences in programme impact for different participants and (vii) providing insight into how programme participants experience the value of the programme including unintended benefits that were not part of the originally defined programme goals.

The linear cause and effect model on which the pre/post survey and other quantitative designs are based cannot capture the complexity of the complex, dynamic and nonlinear systems in which public health interventions operate (Patton, 2008). A known or postulated underlying mechanism by which the programme activities cause change in measured outcomes is critical in judging causality and this requires evidence beyond looking at the relationship between quantitative variables (Davidson, 2005; Hennekens, Buring, & Mayrent, 1987). The in-depth qualitative approach of the case study and literature review combined provides critical evidence to support the association between the intervention and change measured quantitatively. How the programme worked to contribute to outcomes in a specific context is key not only to supporting causation and attribution but it also provides critical information for potential adaptation and replication of the programme to other settings (Patton, 2008, p. 449).

The case study methodology through ‘thick’ description, understanding of programme context, identification of the key factors in particular settings that lead to precise outcomes, and the ability to uncover a sequence of events (Simons, 2009) can provide evidence for causality (Davidson, 2005; Yin 2014). By representing the programme in action and accounting for contextual factors of both time and place (Simons, 2009), case studies can enable the identification of patterns and elements that link a

programme to theorised outcomes elicited from the literature and can provide evidence for a postulated causal pathway or causal chain of events (Davidson, 2005; Yin, 2014).

A simple programme model for MRT with an emphasis on programme components and features that contribute to ‘subjective wellbeing’ in participants was developed from the evidence of the evaluation case study and literature review (Fig. 1).

The figure shows the six model components of the MRT programme as it is currently operating. Model features were identified through the evaluation case study and the literature was used to link these features to outcomes, an outcomes chain and theory of change (Funnell & Rogers, 2011) supported by the literature review. The evolved programme was closely connected to best practice documented in the literature. This model is somewhat removed from the specific context of the MRT programme and for application elsewhere also requires ‘thicker’ description to both: (a) better understand the boundaries of the programme within its wider context and (b) increase understanding of the complexity of how the programme worked in this setting as documented by the case study narratives. For

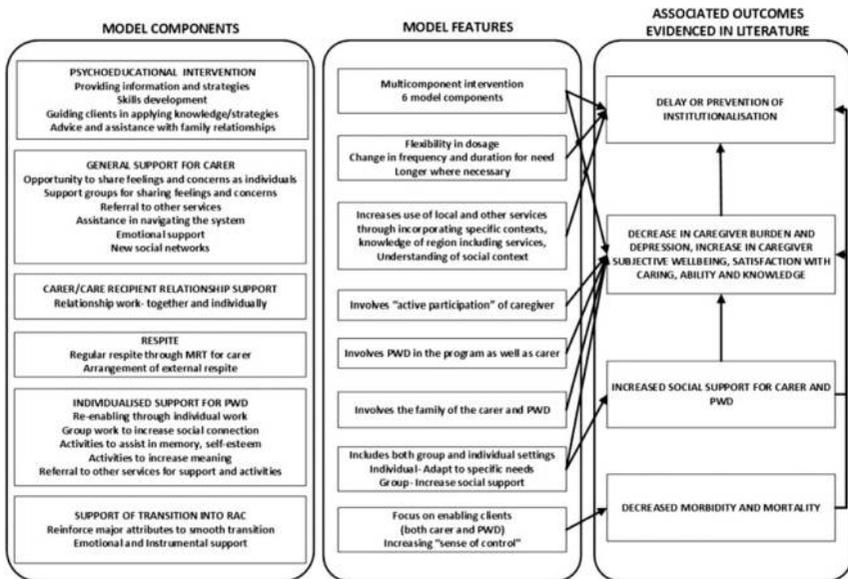


Fig. 1. Operational Model of the MRT Programme Developed through the Evaluation Case Study and Literature Review.

example, the stigma of dementia experienced in the broader population and the impact of this stigma on service providers relationship with Alzheimer's Australia and the MRT service and their response in referring to MRT and the timing of referrals is an important component of a theory of change that is not included in the model. Likewise, key to the programme's success are the personal characteristics of the two-member MRT team, their compatibility and strength of their relationship, their experience and skills in communication and building strong connections to clients and stakeholders. This is consistent with the finding of Greenhalgh and others who showed the importance of individuals and relationships to sustaining service innovations (Greenhalgh et al., 2012). These working relationships do not feature in the literature and were not explored in-depth in the MRT evaluation case study described here.

The information elicited to provide a basis for partial understanding of the causal mechanisms of the programme also enabled in-depth investigation of programme processes. This mechanism and process information is within the same 'black box' and supports the approach of simultaneous evaluation of programme processes and programme value.

The case study approach together with the literature enabled the determination of some of the key components of a 'theory of change' for the programme (Funnell & Rogers, 2011) and identification of factors impacted that contribute to change in the outcome of 'subjective well-being'. For example, changes experienced by participants and documented through their narratives included improvement in knowledge about dementia and development of new relationship skills. The participant narratives provided evidence that these improvements in turn contributed to the well-being and sense of control of both carers and PWD. Nancy (pseudonym)¹, a woman in her mid-sixties and carer of her husband, describes the new knowledge and relationship strategies she gained:

'I said I didn't want to get to the hate and resentment stage. This was my aim. (MRT) helped me a lot to try to keep the openness between Bill and I. It made a difference. It gave me the strength to look at the relationship from a different point of view. It made me see that dementia acts on the personality in a way that makes them angry and resentful ... (MRT) gave me the strategies based on their experience. Sometimes what they told me was effective and sometimes I got into defensive mode and it didn't work'.

A stakeholder working for a state government service observed that Nancy was caught in her own situation and perspective and that the MRT helped Nancy develop an understanding of Bill's situation and 'took the emotionality out of it for Nancy and kept things grounded'.

These narratives show the value in identifying intermediary influences such as change in knowledge and relationship skills that may show a difference before QoL does, and are less affected by carer's continually changing life situations. However, dementia knowledge and relationship skills, like QoL are also affected by the context of deterioration of condition of the person they are caring for and the increasing challenging behaviours that accompany it.

Confounding influences on programmes that quantitative approaches to evaluation strive to 'control for' are often not separable from either programme features or the social and cultural context in which they occur. 'Controlling' for these factors in quantitative analysis is flawed. Rather, an understanding of the context through 'thick' description is critical.

For example, the MRT case study showed that decreasing social networks and social support resulting from a dementia diagnosis and progression of the illness had an impact on the subjective well-being of both the carer and the PWD. This finding of 'shrinkage' of social networks and social support following a dementia diagnosis is supported by the literature (Brodaty & Hadzi-Pavlovic, 1990; Lilly, Richards, & Buckwalter, 2003). However, 'controlling' for diminishing social networks and support as 'confounding factors' in quantitative analysis would be erroneous because simultaneously the MRT programme was facilitating an increase in related social networks and social support through several programme components. The changing experience of social networks and social support for MRT clients is complex and can only be understood within the context and lived 'real world' experience of the programme participants. The narratives show that social support is both a challenge to and strength of the programme.

George is one of the carers whose experience was explored through the case study. He is in his seventies and considers himself an introvert who through over 50 years of married life, relied on his wife Joan, who has dementia, for direct support as well as for social links to friends and neighbours. The only social activity he attended on his own was golf and he had to stop this to care for Joan as her dementia progressed. George explains the changing support he experienced through the advancement of Joan's dementia and involvement in the MRT programme:

'Most people don't want to know about it (the dementia). Friends stopped coming ... I can't imagine what it would be like if I'd been completely on my own. Especially for me, I don't have many friends'.

The MRT workers provide a relationship of emotional and instrumental support to both the carer and PWD. This is consistent with the

primary source of support for the elderly being shown to be a confident who provides both emotional and instrumental support who is usually a relative (other than spouse or children) or close friend (Seeman & Berkman, 1988). The relationship with the MRT worker is an even more critical confident relationship given the stigma associated with dementia and the reluctance of people to discuss the situation even with those they are close to. In addition, through the regular social groups for carers and PWD provided as part of MRT, new social networks and avenues of emotional support are facilitated. These avenues of support critically replace lost sources of social support and have a substantial impact on both the carer and PWD. Four years after they first received assistance from MRT, Joan was placed into residential aged care (RAC). Six months later, George continued to attend the carers support group, Carers' Catch up and he says:

'I need (Carer's Catch up) more than ever before. I am lonely ... I am introverted ... I look forward to it because there is not much else I do, except playing golf once a week'.

A key finding from the case study was that the reluctance of people to acknowledge dementia in themselves, the person they care for and family member because of the fear and stigma that a dementia diagnosis brings with it. In the rural context in which the programme was situated, this fear was exacerbated by the fear of community gossip and social repercussions. As one of the carers, Sandra says:

'My daughter encouraged me to see (Alzheimer's Australia) about a year before I actually came in to see (MRT) ... I felt like a fool to have left it so long ... When you have a partner with Alzheimer's it is like the leper's bell ... You walk down the street and people will say hello and cross the street. They do it no matter what people say'.

The narratives also revealed the difficulty and delay in getting a diagnosis when family members suspect the person has dementia, the reluctance of general practitioners to refer to either Alzheimer's Australia or a geriatrician, and the deficit of communication between general practitioners and geriatricians. By the time PWD and carers enter the service, the dementia is often already at a stage of moderate to severe cognitive decline reducing the effectiveness of the intervention. Understanding the social context contributing to late referrals to MRT through participants' narratives contributes to a broader theory of change and sheds light on processes of participant recruitment and strategies for increasing recruitment at earlier stages of the disease including highlighting the need to improve referral pathways to the MRT service.

Another strength of case study is in understanding the differences in programme impacts for different individuals, something that aggregation of quantitative data masks. For example, the randomised control trial (RCT) looks at average results of the treatment group compared to control group and the majority of RCTs in evaluation yield findings of no significant difference between treatment and control (Chen, 2007; Rossi, 1987; Syme, 2004). RCTs are not able to explain different levels of outcome within a programme (Patton, 2008).

The in-depth study of the lived experience of the programme of different participants shows that they experience the MRT programme and programme outcomes in different ways. Capturing these differences provides an increased understanding of how the programme works to affect change. The PWD and carers are all individuals who respond differently, have unique relationships with each other and unique family situations. For example, in contrast to George and Joan who have been married for more than 50 years and have a supportive daughter who was also involved in MRT, Nancy and Bill's is a second marriage and they both have grown children from their first marriages. At the time of Bill's diagnosis, Nancy was recovering from a serious illness and Bill had been her carer. Bill's children were not supportive of Nancy and a son who visited them regularly has a diagnosed mental illness. Bill and his son had both increased their drinking and his son's visits to their home had become an increasing concern, and although he was never a particularly violent man in the past, with the progression of dementia he had been acting increasingly violently towards Nancy. Even though she still loved him, Nancy had started to consider leaving Bill as she was struggling to cope both emotionally and physically in her relationship with him. The lack of family support and the situation of violence contributed to the need for Nancy to be supported in placing Bill in RAC at an earlier stage of the progression of the dementia than was the case for other clients. As one service provider says, 'There could have potentially been a quite dramatic unfolding with Nancy's extreme fatigue and stress and Bill's anger and reactivity. As a worse-case scenario there may even have been (increased) physical violence which would have left both of them more damaged'.

The different real life circumstances of Nancy and George has an impact on the extent to which Nancy's 'ability to care' could be improved as measured quantitatively as a result of the MRT intervention. George was able to gain skills and utilise the support of the MRT service to improve the way he related to and cared for Joan and further delay RAC placement. But the violence Nancy was experiencing meant she was no longer able to

care for Bill. As a result of Bill's placement in RAC, Nancy feels safer in continuing her relationship with Bill, regularly visiting him in RAC and taking him out to lunch and for drives in the countryside. A few months after Bill's placement, Nancy and Bill retook their wedding vows. Nancy has gained control over a home situation she could no longer predict and in a broad sense her 'ability to care' also increased, although it did not continue in the home setting.

Although a major goal of the MRT programme through increasing PWD and carer quality of life and ability to care was to delay placement of PWD into RAC, paradoxically one of the major strengths and benefits of the programme was its assistance with the transition into RAC. This assistance that commenced at the time of initial client entry into the programme was not a direct part of the causal pathway to delay placement into RAC and is not included as a component of dementia caregiver interventions reviewed in the literature. However, assisting this transition is an important component of reducing stress and engendering a 'sense of control' for one of the most stressful life events people experience. The reality is that the majority of PWD will progress to a point where they can no longer be cared for at home and unlike other dementia carer interventions reviewed through the literature, MRT has evolved to incorporate this reality and a plan for this transition early in their service to clients.

The case study showed that MRT are able to reinforce the four major attributes that have been shown to predict a positive experience when moving into residential care: (i) anticipation, (ii) participation, (iii) information and (iv) exploration (Nolan et al., 1996). In George and Joan's case, MRT first assisted Joan's placement into RAC a couple of years prior to the transition by building up trust between both the MRT workers and both George and Joan. They assisted them with organising respite care at a facility that was later able to offer a permanent placement. Predicting the situation the couple would be in after a couple of years MRT assisted in planning respite care that would increase the likelihood of a familiar RAC environment, important for later stages of dementia where change and unfamiliar environments are increasingly traumatic for PWD. In George's words:

'(MRT) were pressing me all the time to have respite, even when Joan was alright, as they knew Joan had to get used to respite as it (placement in RAC) would eventually happen ... They were doing a bit of 'brainwashing' on Joan to bring her around to the idea of going into care ... This was probably a good strategy'.

Both Joan and George participated in choosing a facility and were shown the facility and introduced to staff before respite and almost a year

before eventual placement into RAC. The couple were supported both instrumentally and emotionally on the day of placement and in the early weeks following RAC placement. George and Joan's daughter describe how then when her mother needed to be taken to RAC, MRT staff knew the specific family obstacles and assisted by taking her mother to RAC because her husband of more than 50 years, her carer, would not take her because he knew he would be leaving her there and it was too difficult for him emotionally. The daughter also knew that her mother would not get into the daughter's car when it was time to go, so it was decided Joan would go with the MRT workers. As the daughter explains:

'(MRT workers) had built her trust over the years ... she wouldn't (cooperate with family). She would nod and smile and cooperate (with MRT) ... When they needed to take her to full time care, they knew that she would get into (MRT workers) car. So I met them at the centre ... We thought dad would have picked her up again and taken her home ... so (MRT workers) and I talked about it. We talked about a strategy ... I took dad back to Sydney with me for a while'.

LIMITATIONS

The case of the collective experience of dementia and within this the impact of a mobile programme of support and education in a predominately rural area grew from the investigation of the programme experience of 'individual cases' of carers and PWD. As the interview extracts show, the broader case is mapped out through the in-depth interviews with carers and then explored through interviews with family members, staff and other service providers. The 'thick description' from the perspective of carers thins out around the edges of the collective case and limited the development of a theory of change that encompasses the true complexity of the bounded programme within its broader context. For example, the stigma experienced by individual carers such as Sandra is a manifestation of the stigma of dementia in the broader social context. This stigma is linked to not only to decreased social networks for the carer and the reluctance to seek assistance and a diagnosis but also to the reluctance of medical practitioners to diagnose the condition and of family members and friends to acknowledge it. It is stigma related to the broader dread of getting dementia of people within any Australian population, affecting what family members, friends, neighbours, medical practitioners and other services providers understand and how they act.

Investigation of living conditions, relationships, service interactions through observation and more depth in the interviews with service providers and family members would have provided valuable perspectives, a thicker description of the case and the development of a more complete theory of change. Even with its limitations, the MRT evaluation case study unravels some of the social, cultural and political context within which people experience the programme. This demonstrates both programme value through identifying key components of a theory of change and evidence of causality and maps key programme processes and the programme model for application elsewhere. Broadening the thick description of the case study to include the outer boundaries of the case by incorporating in-depth interviews with programme management, service providers, medical practitioners and specialists and family members would provide true triangulation of perspectives and exploration of all facets of dementia care. This greater understanding of the bounded system would add value to understanding the contextual conditions and a more complete theory of change for application of the programme elsewhere.

Much would be gained through exploration of the relationships between MRT staff and other service providers including the importance of different personal attributes of workers and the impact of this on how they work together. More in-depth understanding of how MRT staff navigated the additional stigma of institutionalisation of loved ones to include as a key programme element an increased familiarity and smoothed transition for PWD into RAC would be of value. The 'balancing act' of gently planning and supporting the transition to institutional care within the context of a highly stigmatised condition (dementia) and a highly stigmatised and emotionally loaded act (placement in RAC) is a critical attribute of the programme requiring more in-depth study.

CONCLUSION

The example of the MRT evaluation demonstrates many benefits of case study to evaluation practice including: the flexibility to answer many key evaluation questions and to address evaluation of process and outcome simultaneously, ability to uncover valuable but unintended programme benefits and to increase the strength of the evaluation to empower participants and communicate to current and potential stakeholders through understanding the value of the programme from the lived experience of participants.

Through the application of a case study, the evaluation was able to address key questions, not only the ‘how?’ and ‘why?’ the programme has impact, but also lends support for the ‘what’ impact the programme has by illuminating a theory of change and providing evidence of causation and effects earlier in the causal pathway to ‘subjective wellbeing’. The importance of the evaluation practitioner having the case study in their evaluation ‘tool box’ is that it reduces the danger of the method driving the evaluation questions being asked (Cook et al., 2010). Through a utilisation-focussed approach to evaluation, the questions to be addressed are negotiated first with clients of my evaluation practice well before methodological considerations (Patton, 2008, 2012).

The MRT case study analysis shows how complex multiple interacting processes generate outcomes, for example, how the emotional and instrumental support provided by MRT buffered the loss of support from family, friends and community and became a ‘life-line’ of support to carers through an increasingly difficult life journey. This is consistent with the call for more complex approaches than the investigation of simple links between independent and dependent variables to address how multiple interacting processes generate particular outcomes over time (Greenhalgh et al., 2012). Pragmatically, the case study provides evidence of causation in the situation of small sample size as a result of the nature of a relative small programme and short evaluation time frame in the case of the MRT evaluation. In addition, it addresses the known limitation of quantitative methods in yielding findings of significant differences (Chen, 2007; Rossi, 1987; Syme, 2004).

The importance of understanding programme processes including the systemic and contextual characteristics of programmes and their evolution, such issues of staffing and relationships within programmes, has been emphasised in recent evaluation literature (Greenhalgh et al., 2012; Linnan & Steckler, 2002). The MRT evaluation case study showed that the programme had evolved over 10 years to include key programme characteristics that have been shown in the literature to be linked to positive programme outcomes such as ‘active’ participation of the care giver and inclusion of both individual and group programme components.

The application of a purely goal focussed quantitative approach to the evaluation of the MRT programme would have ignored the programme component of supporting the transition of PWD to RAC, or ironically ‘controlled’ for it as a negative confounder of the relationship between the defined and funded programme objectives and ultimate goal of delay in RAC placement. The support of this transition to RAC is ethically

important, identified as one of the most critical components of the programme by carers and family members. This evolved programme component addressed a major gap in services for carers and PWD. The MRT case study supports the importance of the use of evaluation methodologies that have the ability to uncover ‘unanticipated programme side-effects’. In Scriven’s words, ‘side effects are often the main point’ (Scriven, 1993).

Consistent with a traditional case study approach, much of the MRT evaluation report is written from the perspective of participants and in their words addressing a power balance of evaluation and research, whereas from the scientific perspective, reports are written from the outsider ‘expert’ perspective (Syme, 2004). This contributed to substantial engagement of participants including carers, PWD and their families, staff and stakeholders through the process and ownership of and engagement with the evaluation report (including their invited attendance at the launch of the evaluation report) and the future of the programme. It acknowledges ‘the critical contribution of “engaged” human agents’ in building and maintaining changes observed through evaluation (Greenhalgh et al., 2012). Ethically, increasing the power of the voice of programme participants who are experiencing a loss of voice through the devastation that dementia reeks on their lives rather than exacerbating the loss of power to another ‘expert’ outsider is important.

Despite the evident strengths of the in-depth case study, bias towards quantitative methods and against narrative and qualitative ways of knowing continues not only in the academic realm (Cook et al., 2010; Scriven, 2008) but also in the community at large. It is puzzling that although we live by narrative every day and every minute of our lives and it is our way of working through a chaotic world, it appears that we are more convinced by science and numbers when it comes to making decisions. I planned to include an example of a much larger programme evaluation I conducted recently for a client to lend support to the strengths of the case study method documented in this chapter. The (extensive) quantitative evaluation showed (overall) ‘no significant impact’ but a rigorous qualitative case study component demonstrated the merit of the programme in shifting participants towards the outcomes in a difficult context of competing factors in their lives and documented immense programme benefits for some. I requested that I use this example as part of this chapter. Much to my surprise, the reply I received from the client, albeit a new staff member, was negative. They said, ‘Given these outcomes are *not positive*, it would be our preference they are not published ... is it possible that the comments are reframed to remove reference to the project and the *adverse* findings’.

The reality is that, the debate of the relative importance and significance of qualitative case study to evaluation is set to continue both in the academic realm and the settings in which evaluation practitioners' work (Cook et al., 2010; Scriven, 2008). There is much to be gained by striving to be 'bicultural' when it comes to preserving the key values of quantitative and qualitative research and maximising the contribution of 'big Q' qualitative research to evaluation (Kidder & Fine, 1987).

NOTE

1. All names used in participant narratives are pseudonyms.

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