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Support for people with dementia experiencing severe responsive behaviours: Unpacking the disconnect between policy and practice

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Abstract

Objective: The Severe Behaviour Response Team (SBRT) program, which was established in 2015 to support aged care residents with dementia experiencing very severe and extreme responsive behaviours received far fewer referrals than projected during its first year. This article describes the outcomes of a brief survey to identify potential barriers to referrals and identify opportunities to improve the uptake of the service.

Methods: A pragmatic, quasi-experimental study was conducted involving clinical leads working in a representative sample of care homes that had not used the SBRT. The study was part of the formative evaluation activities of an ongoing program evaluation.

Results: Of the 53 clinical leads that participated in the survey, one-third had not heard of the SBRT prior to being contacted. The remaining two-thirds ($n = 36$) had not used the service due to the availability of existing resources and concerns regarding responsiveness of, and access to, the new service.

Conclusions: Three themes emerged from the study relating to awareness of the service, responsiveness and the interface between local aged care and health services. Referrals increased following interventions to address the first two themes; however, they continue to remain well below the number projected. This indicates a fundamental disconnection between the policy design process and the day-to-day experience of residential aged care. The study highlights the importance of aged care clinical leads being engaged in dementia policy and program development processes to support improved targeting of resources.

KEYWORDS

dementia, policy, residential facilities, responsive behaviours

1 | INTRODUCTION

The Severe Behaviour Response Teams (SBRT) program was introduced in 2015 to assist Australian aged care homes to provide better support to people experiencing very severe and extreme responsive behaviours—also referred to as behavioural and psychological symptoms of dementia. Despite the anticipated high level of need for the program, referrals in the first year were much lower than projected. As part of the formative evaluation activities underway at the time, a pragmatic study was conducted to understand why clinical leads had not used the service and to identify remedial actions to improve referral rates.

1.1 | Background

In the year the SBRT commenced, 224,115 people were supported in the 192,370 places available across close to 3000 residential aged care homes nationally.[1] Around half (53%)[2] to two-thirds (68%)[3] of these residents were estimated to have experienced moderate or severe cognitive impairment arising from dementia and/or mental health problems. Planning for dementia services is guided by the seven-tiered prevalence and severity model colloquially referred to as the 'Brodaty triangle' (Figure 1),[4] which estimates less than one per cent of people with dementia will experience very severe and extreme levels (Tiers 6 and 7) of responsive behaviours.

Advocates have long argued that, even at its highest levels, care funding is inadequate to support residents experiencing this level of distress.[5] The Dementia and Severe Behaviour Supplement (DSBS) was introduced in 2013. However, this was cancelled the following year after a change in government due to being so highly oversubscribed it was 'unsustainable'.[6] The stakeholder consultation process that followed included a Ministerial Dementia Forum, titled 'Dementia Care—core business for aged care', with a remit to develop options that could be implemented within the DSBS parameters.[7] The outcome was a recommendation to pilot a series of local rapid response teams of 'behaviour management' specialists to provide in-reach support to aged care homes.

The SBRT program was announced the following year with funding of $54.4 million to support an estimated 10,000 residents over 4 years,[8] delivered by a national consortium lead by HammondCare, a large provider of aged care services. Referrals were initially assessed by Dementia Behaviour Management Advisory Services (DBMAS), which, at the time, were delivered by jurisdictionally based providers (mostly public health services). This changed in 2016 when the DBMAS contracts were combined with the SBRT under a new entity Dementia Support Australia (DSA), a service arm of HammondCare. The SBRT service model involves its 'consultants', predominantly experienced registered nurses, 'flying in' to provide on-site clinical support within 48 hours, regardless of location, at no cost to the care home or the resident.

Despite expectations outlined in the SBRT program documentation, the service received less than a quarter (*n* = 460) of its expected 2000 clients in its first year.[9] An independent program evaluation was underway at the time and initiated a study to determine possible reasons for the disparity.

Policy Impact

The low rate of referrals indicates a significant disconnect between the dementia policy and planning processes and the experience of those responsible for clinical care within residential care homes. Future policy processes need to include the perspectives of aged care clinical leads in order to ensure policies and program investments are contextually relevant and able to achieve the goals intended.

2 | METHODS

The study was conducted within the context of the SBRT program evaluation that used grounded theory methodology[10] to support the development of formative and summative findings. A quasi-experimental study[11] was proposed to identify ways to improve referrals to the service. The study hypothesised that the lower referrals could be due to a number of factors, including a lack of awareness of the service, previous negative experience of the DBMAS (thereby impacting on its role as a referral pathway) and/or concerns regarding the utility of the 'fly-in, fly-out' consultancy model.

Given the high levels of unmet need identified within the policy documents and resource constraints within care homes, a pragmatic yet robust approach was planned. This consisted of a brief telephone survey of clinical leads in a sample of approximately 50 care homes that had not used the SBRT. The study design, sampling, data collection process, analysis and consent processes were developed in consultation with the SBRT program management and approved by the University of Wollongong and Illawarra Shoalhaven Health District Medical Human Research Ethics Committee (HE16/076) prior to implementation.

2.1 | Study design

The survey was comprised of seven questions, the majority of which offered tailored response options, with a limited requirement for expansive commentary (unless preferred by the respondent). Questions 1–4 related to respondents' role, level of awareness of and satisfaction with

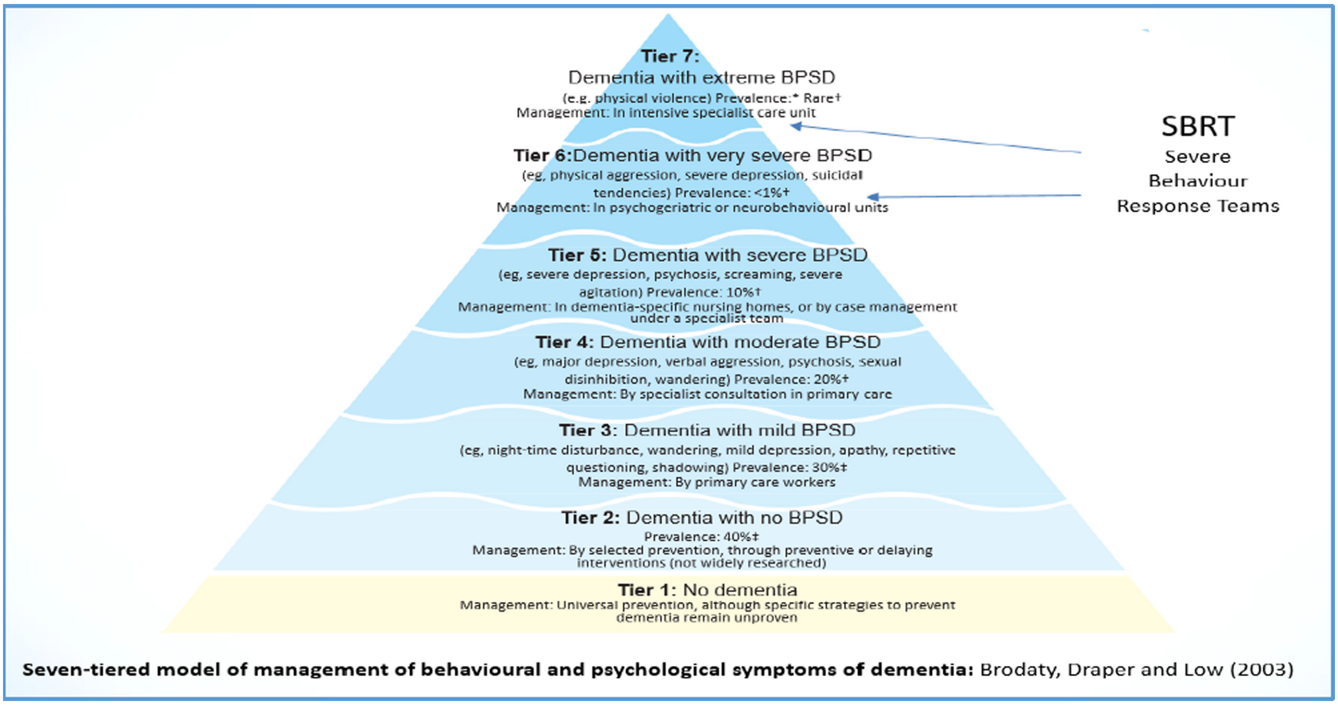


FIGURE 1 Seven-tiered symptom severity and prevalence triangle ('Brodaty triangle')

DBMAS to ascertain what impact, if any, this may have had on decisions regarding referral to the SBRT. Question 5 related to awareness of the SBRT. If respondents were unaware of DBMAS (Question 2) or SBRT (Question 5), they were offered the opportunity to provide additional comments, thanked for their time, and the survey was terminated at that point. Question 6 focussed on reasons for non-referral to the SBRT, and Question 7 explored existing capabilities of the care home to support people with significant responsive behaviours. The survey was piloted with five aged care clinical leads in late January 2017 and was found appropriate for implementation. The survey instrument is in Figure 2.

2.2 | Sampling

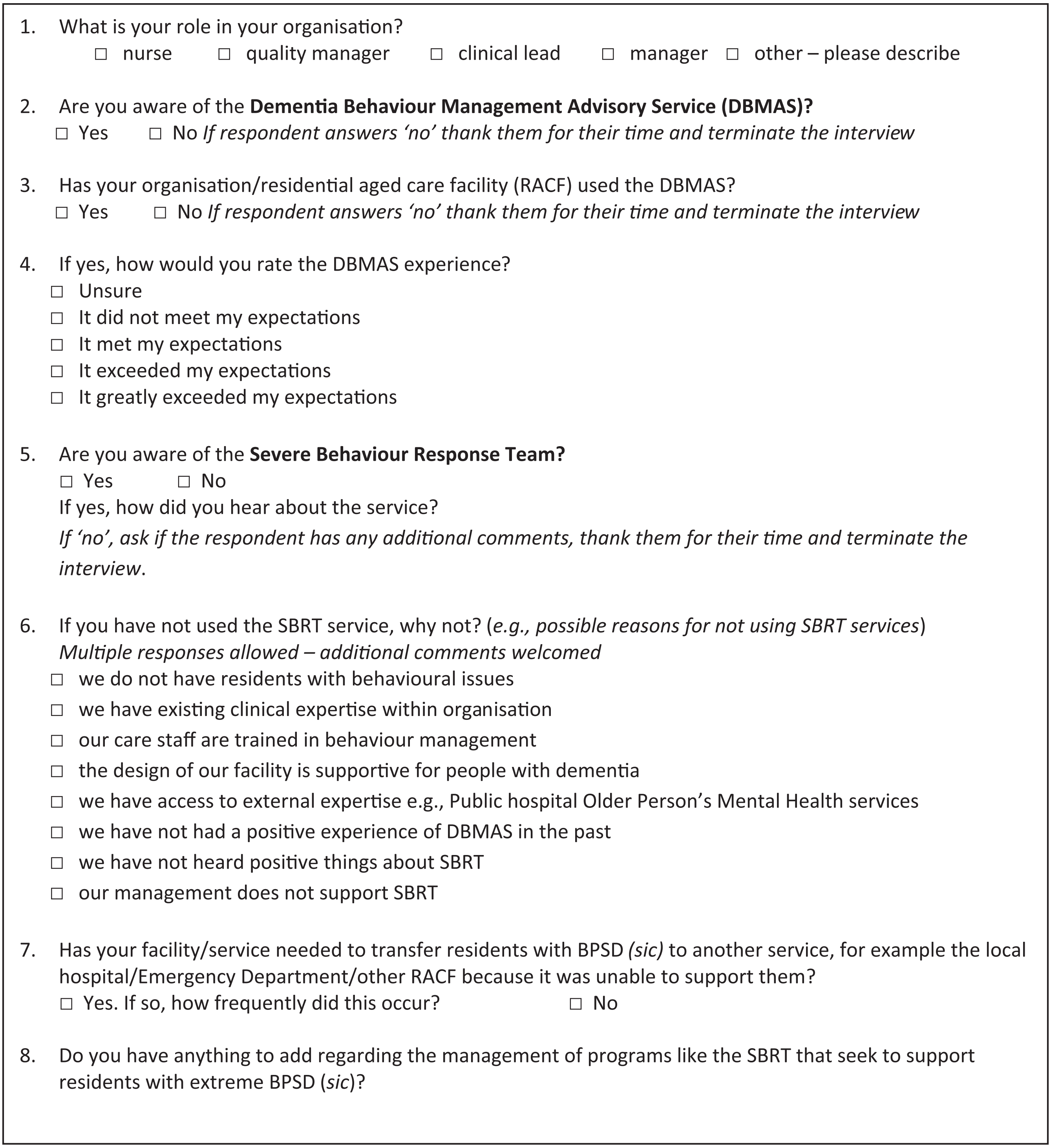
A list of all care homes that had not referred clients to the SBRT ($n = 2534$) was provided by the program data manager within HammondCare. Sampling used proportional allocation stratified by State/Territory, Australian Standard Geographical Classification and sector (government, not-for-profit and private for profit), to ensure sufficient representation of those jurisdictions with very small numbers of care homes. Simple random sampling and rounding of proportions within each stratum resulted in an overall sample of 75 care homes from which to draw the 50 respondents required for the study.

2.3 | Implementation

The survey was conducted between 31 January and 6 March 2017 by two experienced aged care researchers who were responsible for the recruitment of participants and asking the survey questions, as well as data entry. The target number of participants was reached (at $n = 53$, just over the initial estimate of 50) after 64 of the sampled care homes had been approached. Those who declined to participate ($n = 11$) did so due to time constraints and/or relevant personnel being unavailable within the timeframe of the study. All who agreed to participate declined the offer of a call back at a more suitable time. They were provided with a summary of the participant information sheet, verbally assented to take part and were asked the survey questions at that time, consistent with ethics approval. The surveys took between 5 and 15 min each to complete, and data were collected and managed using the University's secure Research Electronic Data Capture (REDCap)[12] database.

2.4 | Data analysis

A formative research approach was applied using descriptive statistics to analyse the quantitative survey responses. These data were extracted from the REDCap database and analysed using SAS software, version 9.4 for



1. What is your role in your organisation?
☐ nurse ☐ quality manager ☐ clinical lead ☐ manager ☐ other – please describe

2. Are you aware of the **Dementia Behaviour Management Advisory Service (DBMAS)?**
☐ Yes ☐ No *If respondent answers 'no' thank them for their time and terminate the interview*

3. Has your organisation/residential aged care facility (RACF) used the DBMAS?
☐ Yes ☐ No *If respondent answers 'no' thank them for their time and terminate the interview*

4. If yes, how would you rate the DBMAS experience?
☐ Unsure
☐ It did not meet my expectations
☐ It met my expectations
☐ It exceeded my expectations
☐ It greatly exceeded my expectations

5. Are you aware of the **Severe Behaviour Response Team?**
☐ Yes ☐ No
If yes, how did you hear about the service?
If 'no', ask if the respondent has any additional comments, thank them for their time and terminate the interview.

6. If you have not used the SBRT service, why not? (*e.g., possible reasons for not using SBRT services*)
Multiple responses allowed – additional comments welcomed
☐ we do not have residents with behavioural issues
☐ we have existing clinical expertise within organisation
☐ our care staff are trained in behaviour management
☐ the design of our facility is supportive for people with dementia
☐ we have access to external expertise e.g., Public hospital Older Person's Mental Health services
☐ we have not had a positive experience of DBMAS in the past
☐ we have not heard positive things about SBRT
☐ our management does not support SBRT

7. Has your facility/service needed to transfer residents with BPSD *(sic)* to another service, for example the local hospital/Emergency Department/other RACF because it was unable to support them?
☐ Yes. If so, how frequently did this occur? ☐ No

8. Do you have anything to add regarding the management of programs like the SBRT that seek to support residents with extreme BPSD (*sic*)?

FIGURE 2 Telephone survey

Windows, SAS Institute Inc., Cary, NC, USA. Qualitative data involved systematic text condensation[13] which included the two study members who implemented the survey, coding one-quarter of the free text from the surveys; this process assisted in checking the validity of the categories and eliminating any ambiguities and misunderstandings in the coding process. Once a set of categories and codes were agreed upon, one member of the research team coded the remaining surveys. After the data analyses were completed, the same two researchers met again to discuss the results. Data and findings were then discussed by the broader program evaluation team ($n = 7$) to identify any gaps, overlaps or implications for ongoing evaluation activities.

TABLE 1 Distribution of telephone survey respondents

State	Major cities			Regional[a]			Remote Australia[b]		Total	
	Government	Not for profit	Private for profit	Government	Not for profit	Private for profit	Government	Not for profit	*N*	%
NSW	0	8	2	1	5	1	1	0	18	34
VIC	1	3	4	2	1	2	0	0	13	25
QLD	0	1	1	0	4	1	0	0	7	13
WA	0	2	1	1	1	0	0	0	5	9
SA	0	1	2	1	1	0	1	0	6	11
TAS	0	0	0	0	2	0	0	0	2	4
ACT	0	1	0	0	0	0	0	0	1	2
NT	0	0	0	0	0	0	0	1	1	2
Total *N*	1	16	10	5	14	4	2	1	53	100
%	2	30	19	9	26	8	4	2		

[a] Regional includes inner and outer regional.

[b] Remote includes remote and very remote.

3 | RESULTS

Care homes that participated in the survey came from a range of geographical settings and provider groups, consistent with the sampling frame (Table 1). All respondents ($n = 53$) were registered nurses, the majority of whom identified as care managers ($n = 29$) and clinical leads ($n = 16$), and the remaining were a mix of team leaders ($n = 4$), quality managers ($n = 2$), one Deputy Director of Nursing and one nurse educator.

3.1 | DBMAS awareness and experience

Almost all respondents ($n = 52$) were aware of the DBMAS, and nearly three-quarters ($n = 38$) had used their local/regional DBMAS service. Of these, two-thirds ($n = 26$) reported that the DBMAS had met or exceeded expectations.

3.2 | SBRT awareness and experience

One-third of all respondents ($n = 17$) had no knowledge of the SBRT prior to being contacted by the study team. These were offered the opportunity to provide additional comments, the majority of whom ($n = 14$) agreed, were thanked for their contributions and the survey terminated at this point.

The remaining respondents ($n = 36$) had been made aware of the service through a range of education and networking activities, government communications and/or promotional activities (Table 2).

3.3 | Reasons for non-use of SBRT

Respondents who were aware of the SBRT ($n = 36$) were asked a multi-response question as to why they had not referred clients to the service. One-third ($n = 14$) provided one reason, while the remaining provided two ($n = 7$), three ($n = 2$) or four reasons ($n = 13$) each. The three main reasons for not referring clients to the service were as follows: clinical leads already had access to local expertise, resources and/or environmental design features within the care home; the care home had no residents who experienced responsive behaviours; and previous negative experience of DBMAS (referral pathway). Just over one-quarter of respondents ($n = 10$) indicated they had no residents with responsive behaviours, mostly ($n = 6$) due to existing clinical expertise and regular staff training. Apart from this, there was no discernible pattern found among the combinations of responses; hence, results are presented based on the frequency ($n = 91$) and the proportion of respondents ($n = 36$) who indicated the response as a reason for non-use of the service (Table 3).

The majority of all respondents ($n = 45$) provided additional comments prior to completing the survey. Around half of them ($n = 24$) raised concerns regarding access and timeliness, particularly in the context of residents experiencing high levels of acuity, risk and distress.

> Facilities have to be skilled when it comes to managing severe behaviours (sic). 'Fly-in, fly-out' is not responsive enough
>
> (PA8)

Respondents from a range of settings across NSW ($n = 6$), Victoria ($N = 2$), ACT ($n = 1$) and South Australia ($n = 1$) raised concerns regarding the role of DBMAS as the referral pathway based on previous experiences of slow response times ($n = 6$) and ineffective support ($n = 4$).

> We would love to use SBRT but can't get past the gatekeeper
>
> (PA7)

One-third of those who were aware of the SBRT ($n = 17$) indicated they did not expect to use the service in the future due to their organisational capacity (access to registered nurses, regular staff training and/or

TABLE 2 Sources of information about Severe Behaviour Response Team (SBRT) ($N = 53$)

Source	Number	%
Education and networking activities	13	25
Department of Social Services electronic newsletters and emails	12	22
Dementia Behaviour Management Advisory Service (DBMAS) communications	5	9
Media release associated with the program launch	3	6
Severe Behaviour Response Team (SBRT) promotional materials (e-newsletter) and events	3	6
Nil—*no knowledge prior to contact by study team*	17	32
Total	53	100

TABLE 3 Non-use of Severe Behaviour Response Team: Reasons ($N = 91$) *reported by* respondents ($N = 36$)

Reasons for not referring to Severe Behaviour Response Team (SBRT)	Responses N^a ($N = 91$)	Responses % ($N = 91$)	Respondents % ($N = 36$)
Internal and/or local capacity, expertise			
We have access to external expertise, for example Specialist Mental Health Services	20	22	56
Our care staff are trained in behaviour management	14	15	39
The design of our facility is supportive for people with dementia	13	14	36
We have existing clinical expertise within organisation	11	12	31
No residents needing SBRT services			
We do not have residents with behavioural issues	10	11	28
Have not needed to use the SBRT as yet	7	7	19
Previous experience of Dementia Behaviour Management and Advisory Services (DBMAS) (*referral pathway for SBRT*)			
We have not had a positive experience of DBMAS in the past	2	2	6
Unable to access SBRT through DBMAS (DBMAS barrier)	2	2	6
Other			
Includes: uncertainty re how to access SBRT, concerns re responsiveness	12	13	33
Total	91	100.0	–

[a] Multiple responses could be provided, and hence, total number is >36.

dementia-enabling design) and existing relationships with local health services (general practitioners, hospital and mental health services).

> (Our organisation) has 2 registered nurses who both work full-time to support residents with dementia across 12 facilities.... The advantage is that the RN knows the facility, the staff and the residents. They are not going in cold.
>
> (PA35)

> (We) liaise with the specialist team at the General hospital. We also have a Nurse Practitioner
>
> (PN5)

4 | DISCUSSION

This short telephone survey was designed to determine why a new and apparently much-needed service did not receive the level of referrals anticipated within its first year of operation. Three themes emerged as follows: variable levels of awareness of the new service, concerns regarding referrals and responsiveness, and the value of relationships between care homes and local health services.

4.1 | Raising awareness of the SBRT

Given the background to the SBRT—high levels of need, cessation of the dementia funding supplement and stakeholder consultation processes—it was expected that care homes would have been eagerly anticipating its commencement. However, around one-third of those surveyed had not heard of the service ($n = 17$) and of those that had, a further third ($n = 13$) were unsure of its scope, scale and/or operational processes. Responding to these findings, additional marketing activities were undertaken and referrals increased from 38 per month (end of the first year) to 52 per month some 18 months later (June 2017).[14] Despite continued promotional activities, referrals appear to have plateaued at around this level, averaging 53 per month at the end of 2019,[15] suggesting that awareness of the service may have been much less of an issue than first thought.

4.2 | Referrals and responsiveness

The second theme supported our hypothesis that prior negative experience of DBMAS had impacted on referrals to the SBRT. Respondents were not only concerned about the inability to directly refer and/or consult with the SBRT, and they also raised questions regarding the capacity of a centrally run service (albeit delivered from most major capital cities) to respond to situations of severe and extreme levels of risk, acuity and distress. Responsiveness was conceptualised in terms of timeliness as well as appropriateness. In regard to timeliness, there was some scepticism, particularly from rural and remote services, that clinical experts could be on-site within the 48-h timeframe advertised (the summative evaluation report[14] did not find evidence to support this). In terms of appropriateness, concerns were mainly in relation to whether an external consultant could provide tailored care management plans for residents they had only just met, and be able to support care staff in organisational contexts and health service networks with which they were unfamiliar.

4.3 | Local capacity and networks

A surprising finding of the survey was the extent to which local resources, organisational and operational features were utilised to support residents at risk of and/or experiencing very severe and extreme behaviours, including:

- regular staff dementia education and capacity building activities
- dementia enabling and supportive environments and
- specialist dementia clinical roles to provide clinical leadership and tailored care planning

The rationale for this focus on local capacity building and environmental design was to reduce the risk of behaviours emerging and ensure residents were supported by appropriately skilled staff who were familiar with their needs, and with whom they were familiar, particularly during times of heightened risk and acuity of need. This also underpinned the preference for working with local health services as it facilitated an understanding among staff of the different organisational contexts and operational procedures (eg referral processes, out-of-hours support protocols), and reflected a shared goal of preventing unnecessary transfers of people with dementia to hospital.

4.4 | Policy design lessons

The attributes of responsiveness and relationships with local health services were central themes of the local 'flying squad' model proposed at the Ministerial Dementia Forum. How then, did these fail to be incorporated in the final program design? To answer this question, it is necessary to reflect on the way the policy question was framed, the parameters of the design process and the priorities of the newly elected government.

Best practice clinical guidelines emphasise the importance of tailored, individualised care management to reduce the risk and severity of responsive behaviours.[16] However, within the policy context, framing behaviours as intrinsic to the individual effectively relegates the extrinsic factors—staffing levels, skill mix, environment—which are predominantly within the remit of government and providers to address, as second-order issues. Additionally, in framing the policy design process as dementia being 'core business for aged care' clearly signalled where government considered responsibility for addressing these extrinsic factors lay.

The parameters for the development of policy options were also clear from the outset. Less than a year before, the government had come to power with an explicit agenda of streamlining government services, reducing the number of public servants and cutting government programs.[17] With the consultation process constraining the development of policy options to within the 'funding envelope' of the former dementia supplement, any proposals to improve the interface between care homes and local health services were also highly unlikely to succeed.

4.5 | Limitations

The backdrop to the study (i.e., a new service, reported high levels of need and resource-constrained contexts) required an expeditious methodology to engage with participants, test hypotheses, clarify barriers and identify solutions. Within this context, the pragmatic sample size ($n = 53$) and sampling methodology was considered sufficient to elicit high-level indicative findings to improve service referrals. The time and resource constraints of the study precluded additional recruitment of participants to explore emerging themes or to validate findings with stakeholders.

5 | CONCLUSIONS

This article describes the findings of a pragmatic telephone survey that was conducted to determine why the policy expectations for a new service designed to address the high level of unmet need in care homes were not realised. Three themes emerged from the survey, related to awareness of the service, perceptions regarding responsiveness and the value of local aged care and health networks. The first two of these—awareness and responsiveness—were subsequently addressed by SBRT program managers, resulting in a marginal improvement in the number of clients now seen by the service (albeit still well-short of initial policy projections). The third—local aged care and health networks—was unable to be addressed due to the constraints applied to the policy design process, which delivered a national program that operated out of major capital cities and was uncoupled from local health service delivery.

The SBRT is an example of aged care policy and practice disconnection. The lower than projected uptake of the service suggests that conceptualisation and implementation failed to incorporate the preferences of aged care clinical leads responsible for supporting residents at risk of and/or experiencing severe and extreme responsive behaviours. This brief study has shown a preference for aged care services to be able to draw on local health networks to support their residents at risk of experiencing behaviours. It also suggests that there is a need to revisit some of the assumptions and processes regarding aged care, particularly the policy and planning regarding dementia services.

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CONFLICTS OF INTEREST

No conflicts of interest declared.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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