

Evaluation of an integrated service delivering post diagnostic care and support for people with dementia and their families.

PIERCY, Hilary <<http://orcid.org/0000-0002-7663-8858>>, FOWLER-DAVIS, Sally <<http://orcid.org/0000-0002-3870-9272>>, COOPER, Carol and DUNHAM, Margaret

Available from Sheffield Hallam University Research Archive (SHURA) at:

<http://shura.shu.ac.uk/21456/>

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

Published version

PIERCY, Hilary, FOWLER-DAVIS, Sally, COOPER, Carol and DUNHAM, Margaret (2018). Evaluation of an integrated service delivering post diagnostic care and support for people with dementia and their families. *Health and Social Care in the Community*, 26 (6), 819-828.

Copyright and re-use policy

See <http://shura.shu.ac.uk/information.html>

Title: Evaluation of an integrated service delivering post diagnostic care and support for people with dementia and their families.

Authors

Hilary Piercy PhD, MA, BSc (hons), RN, RM. Sheffield Hallam University

Sally Fowler-Davis DBA, MEd, DipOT Sheffield Hallam University

Margaret Dunham, PhD, MSc, BA (hons) Sheffield Hallam University,

Carol Cooper DMedSci, BMedSci, PGDipEd, RMN Sheffield Hallam University.

Corresponding author:

Hilary Piercy Department of Nursing & Midwifery, Sheffield Hallam University, 32 Collegiate Crescent, Sheffield S10 2BP

Tel +44 114 2255603

Key words.

Integrated service, dementia care, evaluation research, dementia adviser, admiral nurse

What is known about this topic.

- Dementia care is commonly inadequate and delivery is fragmented
- Integrating health and social care is essential for improving quality and safety of provision
- There is a current lack of progress towards integrated care provision in England.

What this paper adds.

- A novel approach to integrating health and social care provision through a combined Admiral Nursing and Dementia Adviser service.
- Indications of the effectiveness of the pilot service.
- Insights into the key challenges and opportunities associated with this service design.

Abstract.

Greater integration of health and social care services is considered vital to ensure sustainable long term quality provision for the growing numbers of people living with

dementia and their families. Integration of services is at the heart of government policy in England.

We evaluated a new integrated service for post diagnostic dementia care, funded as a pilot and delivered through a partnership of statutory and voluntary sector health and social care organisations. The service used an adapted Admiral Nursing service model with a workforce of Admiral Nurses (ANs) and Dementia Advisers (DAs).

A mixed method approach was used to assess implementation and outcomes. It involved: collection of service activity data; carer reported experience survey data, focus group discussions and interviews with the service delivery team and the management group. Qualitative data was analysed using a framework approach.

37.8% of the eligible population registered with the service over the 14 month pilot period. The self-referral route accounted for the majority of referrals, and had enabled those not currently receiving specialist dementia care to engage with the service. Carer satisfaction surveys indicated high levels of satisfaction with the service.

The caseload management system offered specific benefits. Individual caseloads ensured continuity of care whilst the integrated structure facilitated seamless transfer between or shared working across AN and DA caseloads. The skill mix facilitated development of the DA role increasing their potential contribution to dementia care.

Challenges included managing large workloads and agreeing responsibilities across the skillmix of staff. This model of fully integrated service offers a novel approach to addressing the problems of fragmented provision by enabling joined-up working across health and social care.

Background.

Dementia is one of the top causes of death in England and Wales (Office for National Statistics, 2015) and is a growing health problem. There were an estimated 767,000 people in England and Wales living with dementia in 2016 and this figure is projected to rise to more than 1.9 million by 2040, largely as a result of improved life expectancy (Ahmadi-Abhari et al., 2017).

The outcomes for people living with dementia (PWD) are recognised as being closely tied to the availability of support and the on-going wellbeing of family care givers who are estimated to cover almost half of the care costs as unpaid care and support (Prince et al., 2014). Government policy highlights the importance of providing family carers with access to appropriate support (Dept of Health, 2012) however post diagnostic support for carers is often inadequate and fragmented (Jansen et al., 2009; Robinson et al., 2009) and arguably leads to sub-optimal outcomes and greater demand on acute services.

A major challenge for the health and social care system in England is its ability to offer high-value care in the context of financial pressures and growing demand for care and support in the community. Integrated care is considered essential to meet the needs of the ageing population with long-term conditions (Goodwin et al., 2011), and is at the heart of recent government healthcare reforms. It offers a means by which to address concerns about fragmentation and to enable services to be delivered in a way that is both efficient and cost effective. This is considered vital for sustainable long term quality provision (Goodwin et al., 2011).

Government policy emphasises the need to develop care systems integrated around the needs of the patient through sustainability and transformation plans that bring together local health and social care providers and commissioners (NHS England, 2014). There is no single model for integrated care despite multiple attempts to define the concept (Armitage, Suter, Oelke, & Adair, 2009; Ham & Curry, 2011). It is best understood as an approach that seeks to improve the quality of care for individual patients, service users and carers by ensuring that services are well coordinated around their needs (Shaw, Rosen, & Rumbold, 2011). This approach requires those involved with planning and providing services to impose the user's perspective as the organising principle of service delivery (Lloyd & Wait, 2005; Shaw et al., 2011).

Barriers associated with integration of services are hampering progress towards integrated care provision (Goodwin et al., 2011). A recent Care Quality Commission report identified an overall lack of progress in the extent to which health and social care services across the country are working together to meet the needs of older people and a lack of consistency in sharing of information which makes it difficult to

identify older people at risk of deterioration of health status. It identified the lack of connection between services that results in older people and their families often having to navigate their way through complex provision (Care Quality Commission, 2016) . The report concluded that systems for improvement should be developed locally.

This paper reports the evaluation of an integrated service, introduced as part of a local health and social care strategy to improve post diagnostic dementia care. The aim of the evaluation was to assess how well the service had performed in providing support to PWD and their family/carers and to understand the opportunities, benefits and challenges associated with the integrated service model.

The local context.

The integrated service was established through joint health and social care commissioning arrangements in a large northern town in England, with an estimated population of 302,000 of whom 91.8% were White British according to the 2011 census. The service was funded for 14 months operation plus a two month set-up period and delivered as a pilot service March 2016 - May 2017. Funding was secured by re-allocation of existing resources through the Better Care fund which incentivises NHS and local government to work more closely together (NHS England, 2017). Existing provision consisted of a memory clinic and associated community outreach delivered by the NHS Trust. In addition, a range of voluntary and third sector providers had established and long standing contract arrangements with the local authority, to meet the social care needs of elderly people in the community.

The service aimed to improve post diagnostic care and support for PWD and their families/carers. It was available to all PWD who were living at home and registered with a local GP, a total population estimated from local Care Commissioning Group data to be 1700. The service operated with a single point of access and accepted referrals from statutory, social or informal carer providers or by self-referral.

The integrated service was delivered by a workforce with two distinct roles: Admiral Nurses (AN) and Dementia Advisers (DA). Admiral Nursing is a specialist nursing role providing long term support and care for people living with dementia and their family carers which was developed by Dementia UK (Harrison Denning, K., Aldridge,

Z., Pepper, A., Hodgkison, C., 2017). Dementia advisers provide social support. The DA role was first introduced as part of the National Dementia strategy, to facilitate easy access to appropriate care, support and advice for those with dementia and their carers and is largely provided by the third sector (Clarke et al., 2013). The service was organised around localities with a team of one AN and one DA serving each locality.

The operating structure was adapted from Admiral Nursing services which use a case management approach and a case management system (CMS) (Bodenheimer, Wagner, & Grumbach, 2002; Bodenheimer & Berry-Millett, 2009; Koch et al., 2012). In the Admiral CMS, referrals to the service undergo a triage assessment and allocation to one of two casework categories: 'intensive' or 'maintaining'. Those categorised as 'intensive'; on the basis of high or complex levels of need receive care and support from the AN service. Those categorised as maintaining are helped to access support from other appropriate services. A third 'holding' category relates to those on the AN caseload who do not currently require support (Harrison Dening, K., Aldridge, Z., Pepper, A., Hodgkison, C., 2017).

The service was contracted to 'Making Space', a national charity providing health and social care services for adults, in association with Dementia UK. The workforce was seconded from four other organisations who had an existing organisational structure in the town: Alzheimer Society, Sue Ryder Foundation, Age UK and the NHS Trust. A partnership management group chaired by the service lead from Making Space and involving a manager from each of the other five partnership organisations oversaw operational management of the service.

Methods

This was a mixed method evaluation to assess the implementation and the outcomes of the pilot service. It involved the following four components.

- 1) Activity data routinely collected by the service. This included numbers and details of those receiving care, incoming and onward referral information and workload allocation information.
2. Carer reported experience assessed by postal survey. Two separate questionnaires were developed. The AN questionnaire addressed three aspects of

the carer role through 16 questions. The DA questionnaire was shorter with four questions focusing on practical aspects of support. Carers were invited to complete either the DA or the AN questionnaire (determined by whose caseload they were allocated to) within two to six months of registering with the service. The survey was administered by the service.

3) An initial site visit by the evaluation team which involved informal discussions with members of the delivery team and examination of service documents to understand the organisational structure, operating processes and initial challenges of delivering the service.

4) Focus group discussion and individual semi-structured interviews with all those involved in the management and delivery of the service were undertaken during the 11th month of the pilot period. This consisted of two focus group discussions (facilitated by HP, MD and CC) and two semi-structured individual interviews (by HP) with the service delivery team. The overall purpose of these was to gain detailed insights into service performance from the perspective of all those involved in its delivery including significant opportunities and challenges. Additionally we conducted one focus group discussion (facilitated by HP and SFD) with the partner management group to understand how well the service had functioned from their perspective.

All interviews and focus groups were semi structured using a topic guide. Project information sheets and topic guides were sent to participants one week in advance and written consent was obtained from all participants prior to data collection. Interviews were digitally recorded and fully transcribed.

Data analysis

Quantitative data was analysed using descriptive statistics. For the qualitative data, we used framework analysis (Spencer, Ritchie, O'Connor, Morrell, & Ormston, 2014), a pragmatic approach to qualitative data analysis. It follows a systematic five stage analytic process to allow the integration of a priori issues and emerging themes, and provides a clearly defined analytical structure that contributes to the transparency and validity of the results. To ensure rigour, a preliminary thematic framework, capturing the opportunities and challenges associated with the key

aspects of the service, was agreed during project meetings. All members of the evaluation team were involved in coding processes.

Ethical considerations

The project secured approval from a University Faculty Ethics committee as a service evaluation in July 2016. All client specific data was collected by the service and supplied to the evaluation team in numerical and anonymised form to protect confidentiality.

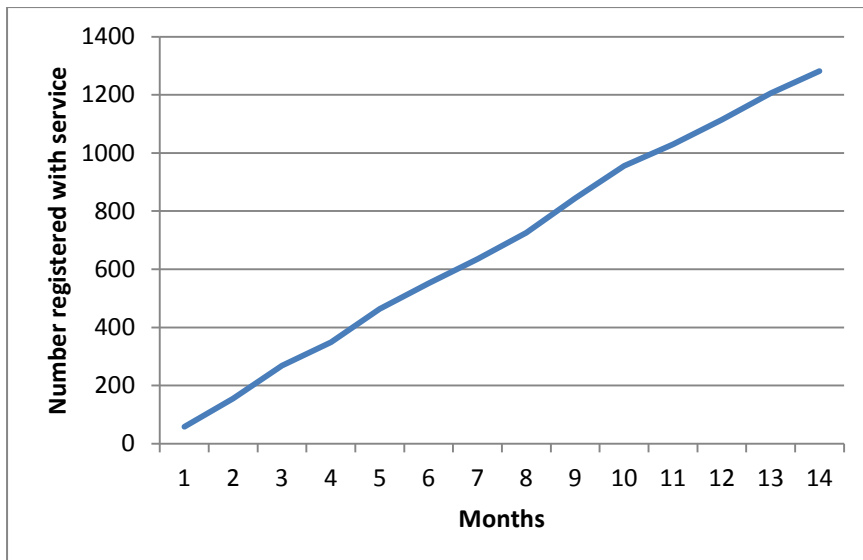
Findings

The findings are organised in three sections: 1) Service use which reports on demand and uptake, 2) Carer experience which reports findings from the postal surveys, 3) Delivering the service which focuses on the staff perspective and reports on the opportunities and challenges associated with the integrated model of care.

Service use.

The service started receiving referrals immediately and this continued at a steady rate over the 14 months (see fig 1). Most referrals were appropriate and resulted in families being registered with the service. Once registered, they were not discharged from the service unless a change of circumstances meant they no longer met the eligibility criteria. Eighteen referrals did not meet the criteria and were not registered, most commonly because they did not have a diagnosis of dementia (n =7), the PWD was living in a care home (n = 4) or they were not registered with a local GP (n =2). At the end of the pilot period, a total of 1282 people were registered with the service of whom 644 were PWD and 638 were carers. Based on the total known population of PWD who were living at home, which totalled 1700, this equates to 37.8% of the eligible population of PWD living at home.

Figure 1: Numbers registered with the service over the pilot period



Dementia diagnoses were recorded for 343 service users. Of those, 31% (n = 106) were vascular dementia, 27% (n = 92) were Alzheimer's disease, 7% (n = 23) had a mixed diagnosis of vascular dementia and Alzheimer's disease with the remaining 36% (n = 122) being other or unknown.

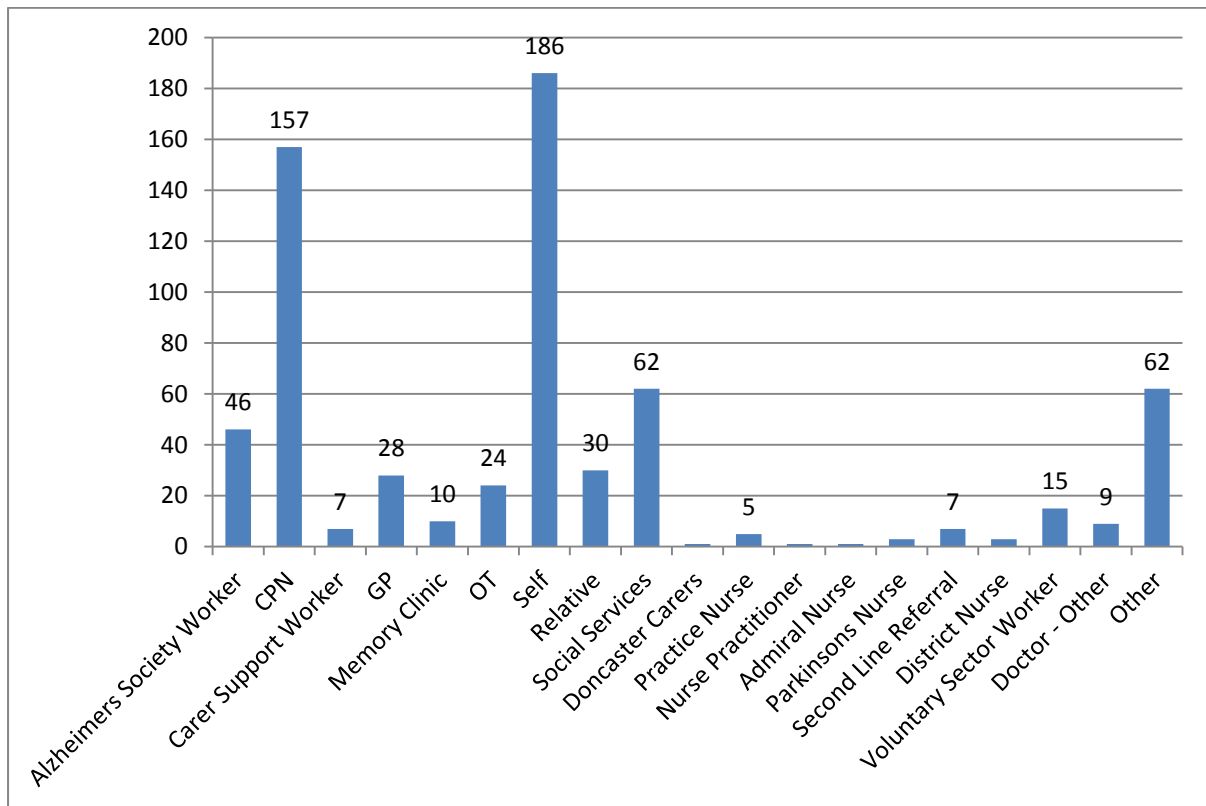
Ethnicity was recorded for 913 service users. Of those, the majority were White British (97%, n = 889).

Of the 1017 for whom age was reported, 74% were over 65 and 27% were over 85 years of age. Separate age data for PWD and carers was not available.

In most cases, the family units registered with the service consisted of one carer and one PWD. A small proportion of PWD registered with the service did not have a registered family carer.

As Figure 2 demonstrates, the service received referrals from nineteen named sources. Lay referrals were most common with self and relative referrals collectively accounting for one third (33%) of the total. Referrals from the Community Mental Health Team (CMHT), the second most common source, accounted for nearly one quarter (24%) of the total.

Figure 2: Number of referrals from each referral source.



User reported experience

The response rate for the AN satisfaction survey was 54% (84/155). The results are presented in tables 1-3. They indicate high levels of satisfaction, with the majority of respondents reporting benefit across all three areas of care and support. Over 90% reported that the ANs were helpful in recognising and supporting their emotional needs as a carer (94%) and the emotional needs of the person they are caring for (91%).

Table 1: Admiral Nurse support with emotional and physical needs

Was the dementia nurses helpful in recognising and supporting...

	Yes	No	Don't Know/ Not Sure	N/A
Your emotional needs as a carer? (n = 68)	64 (94%)	1	2	1
The emotional needs of the person you care for? (n =67)	61 (91%)	1	1	4
Your physical needs as a carer? (n = 68)	58 (85%)	1	4	5
The physical needs of the person you care for? (n = 68)	46 (68%)	1	6	6
Your social needs as a carer? (n = 69)	59 (86%)	2	4	4
The social needs of the person you care for? (n = 69)	58 (84%)	2	4	5

Table 2: Admiral Nurse support with dealing with dementia

Was the dementia nurses helpful in recognising and supporting

	Yes	No	Don't Know/ Not Sure	N/A
Signs and symptoms of dementia (n = 84)	71 (85%)	1	1	11
The impact of dementia on all those involved (n=84)	74 (88%)	2	3	5
Ways of responding to and coping with changes in behaviour (n = 83)	68 (82%)	1	8	6
Understanding the impact of caring for someone with dementia (n= 84)	74 (88%)	1	5	4
Relevant services and support agencies and how to access them (n = 82)	69 (84%)	1	8	4
Medicines and their effects (n = 82)	48 (59%)	8	14	12

Table 3: Admiral Nurse support with the caring role

Was the dementia nurses helpful in recognising and supporting

	Yes	No	Don't Know/ Not Sure	N/A
Offering advice, guidance and support with caring for someone with dementia? (n=82)	79 (96%)	1	1	1
Offering strategies to help you cope with caring? (n = 82)	70 (85%)	1	7	4
Helping promote the wellbeing of the person you care for? (n= 82)	74 (90%)	1	4	3
Exploring the impact of dementia on the family as a whole? (n=77)	58 (75%)	3	10	6

The response rate for the DA satisfaction survey was 60% (92/153). 90% (76/85) had benefitted from support for their practical needs, 93% (84/90) had benefitted from timely and relevant advice and information, 71% (84/90) reported that the DA had been helpful in minimising barriers to accessing support and 72% (63/87) reported they had been helpful in supporting improved quality of life.

Delivering the service

An overview of participants

The service delivery team consisting of three ANs (including the service lead), seven DAs (providing five full-time roles) and the service administrator all participated in the focus group discussions and interviews.

A partner representative (PR) from all six organisations participated in the management team focus group.

This section focuses first on the opportunities and benefits arising from the service design and then on the key challenges associated with delivering the service.

Participants are identified by role (AN, DA, or PR) and number.

Opportunities and benefits.

1. Ensuring accessibility.

Staff reported that a single point of access with multiple referral routes had worked well. Self-referral had been widely used and was considered particularly valuable in ensuring accessibility. Referral patterns included sporadic influx of self-referrals from specific areas suggesting that awareness of the service had been spread through social networks and there were indications, by verbal report, that primary care practitioners were encouraging self-referral rather than go through the referral process themselves.

The value of the self-referral route was particularly highlighted for those with a diagnosis of vascular dementia. Previous commissioning arrangements had not enabled the community mental health team (CHMT) to provide ongoing care and

support for this group of people, with the result that *'they weren't actually being picked up or being supported.'* (PR1) The new arrangements and the lay referral route had offered them a way back into services enabling them to receive the care and support they needed.

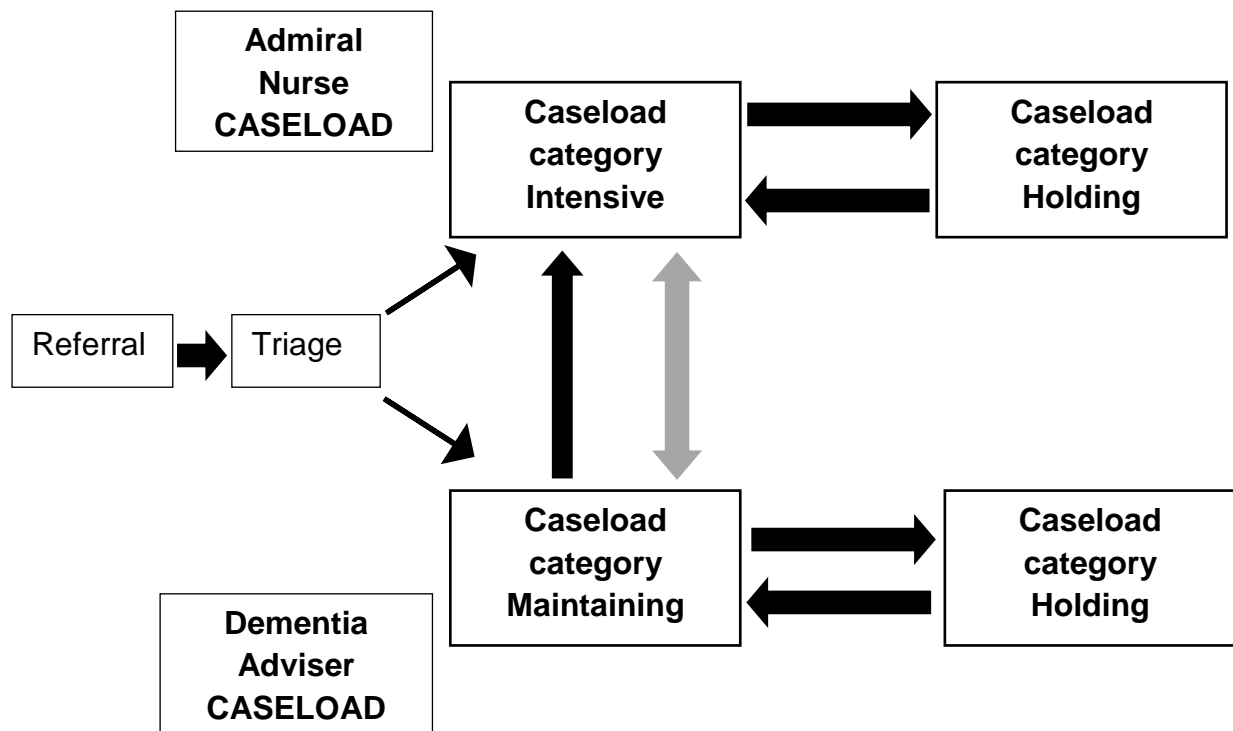
A high percentage of the referrals that we've had are for people with vascular dementia who were perhaps diagnosed five years ago, and then they've had nothing really. Those people have now got the support of this service. It's made such a big difference to their lives, and feedback that you get from the families and from other professionals is really good (AN 1)

2. Providing long term care and support.

The service used an adapted form of the Admiral CMS to provide long term care and support for all families. Following triage by one of the ANs, all referrals to the service were triaged. They were assessed as having an Intensive or Maintaining category of need and on this basis allocated to either an AN or DA caseload respectively.

Individual caseloads were largely fixed and managed by moving families from the active categories (intensive or maintaining) to the holding category when care and support needs resolved and then back to the holding category when other issues arose (see Fig 3).

Fig 3: The integrated caseload management system.



Participants identified specific benefits of this caseload approach. The continuity of care and support it offered was considered a *'selling point of the service... which you don't get from anywhere else'* (DA 2), and provided families with *'a lifeline, enabling them to feel as though they have somebody'* (AN 2). That continuity enabled staff to deliver the service in a way that was based on long term supportive and trusting relationships.

The fact that you know that you can be involved with somebody and it's not time limited .. that helps you build the relationships with families....So you might see somebody on an intense level, and you might be seeing them two or three times a week if they're going through a really difficult phase of the dementia. And then that gradually tapers off ... and then most of my families will be honest and say I'm OK at the minute, I don't need you at the minute, I'll ring you if I need you. (AN 1)

3. An integrated care approach

Whilst caseloads were largely fixed, the integrated structure enabled families to be seamlessly transferred between the caseloads of the DA and AN working in their locality when it was indicated. As one of the ANs explained:

If it does get to a point where the work that's being done by the nurse could be done by an adviser then they'll be passed over; the same with the advisers, if it's too intense then it comes up to us. But that's not generally how it works all the time. It's not up and down all the time with everybody. (AN 2)

Transfer between caseloads was not necessarily straightforward. The point at which a case became complex enough to merit transfer from a DA to an AN was not always clearcut.

But there's not really been the description of ... when does this turn to complex and when does this, what's the difference? It's when you're really working with people it's so hard to put ... things evolve over time don't they? (DA 3)

Also, in some cases, although the situation had deteriorated to the extent that AN input was indicated, families were resistant to being transferred because they wanted to maintain the relationships they had established with their DA.

It really should be coming to me, but the family want [the DA] to stay involved because she's been there, well from the beginning I think. So it's difficult to get in when it does become more complex. (AN 3)

The integrated structure provided the possibility for shared working, with an AN and DA both inputting to a family. Two situations were identified where this had been particularly helpful. Firstly, in providing families on the AN caseload with access to a specific DA-led training programme and secondly where circumstances indicated the merit of maintaining DA involvement whilst also providing AN input.

If I realise this carer [who is on my caseload] is not taking in everything that I'm saying to them about coping strategies and managing these behaviours, I would then ask one of the advisers to go out and do the STaRT [Strategies for relatives] programme with them. (AN 1)

A case developed where suddenly the person with dementia was diagnosed with terminal cancer and put on end of life care. So the adviser came to me and said I'm out of my depth, what's going to happen now? So I took that case to work with her, because she's already built that relationship. (AN 1)

4. Shared learning within the team

The composition of the team and the partnership arrangement offered specific benefits to the service. The breadth of organisational knowledge that was available within the team provided them with a comprehensive awareness of available resources and facilities and the means by which to access these.

We've all come from different backgrounds as well... so everyone knows their organisation and what goes on a bit more.... I think that's probably part of the reason why we have been so good at referring people on and knowing what's out there as a group. (DA 4)

The team context also provided training and development opportunities. The DAs benefitted substantially from working alongside the ANs learning new skills and developing confidence in their practice. This in turn enabled them to provide a greater degree of care and support and manage more complex situations which compared favourably with DAs working in other contexts.

I've definitely become more confident, and I think because I'm with [AN] and she does give me opportunities to do things. Things that I wouldn't have done before ... She does, well sort of empower you to do things. So yes, a bit more confidence and just knowledge and things. (DA 3)

I think the dementia advisers in this service opposed to dementia advisers that we have elsewhere in the business, it feels that the dementia advisers because they're co-located are almost up a notch in terms of capability. Because they have that instant dialogue and input from the experienced clinical team, which is inevitably going to improve their knowledge base and skills mix, I think. (PG 2)

Challenges

1. Managing an increasing service caseload

The maintained rate of referral resulted in expanding individual caseloads which became more difficult to manage over the pilot period. It became increasingly important to target resources by actively managing those caseloads. The ANs principally led this process. They capitalised on the relationships they developed with families to negotiate transfer to a holding caseload and used a range of strategies to enable families to increase self-reliance and develop resilience, particularly by identifying and managing potential crisis situations.

We're educating people as to what to do in a crisis ... Something so simple as they know if somebody's behaviour changes to take a urine specimen to the doctor. That saves so much grief....Now we've found that when we go out to see people they might say oh he was 'off it' last week so I took a urine specimen to the doctors like you told me to, and he'd got a urine infection. We've had antibiotics and he's fine. (AN 1)

The DAs found it difficult to manage their caseload in the same way. The nature of their role and the type of support they provided, which was directed towards maintaining wellbeing, was not well aligned with a CMS that indicated temporary withdrawal of input.

We're finding that hard, to put them on holding. You just deal with one thing and then another thing comes up, so they're back on your case list again. So I don't think you can ever put anybody on holding, not with this disease. It's progressive, you can't. (DA 4)

Their approach was to reduce frequency of visits, however, this was dependent on their ability to refer families to other social services within the care pathway. The large number of onward referrals generated by the pilot service compounded pressure on social services and contributed to increased delays in response times for many services. Managing individual caseloads within this context was an on-going challenge for the service.

We need to be able to refer onto other services to free up room for our new people coming in. But we can't always do that... If there were services available we could put them on hold, so maybe withdraw a little bit and not visit as much. (DA 1)

2. Information sharing across the sector.

Information sharing arrangements created significant problems for the service delivery team. The processes associated with securing information sharing permissions and referral procedures were ongoing and had not been fully resolved by the end of the 14 month pilot. The ANs had no access to NHS medical records for those referred to the service and were therefore dependent on the information provided during the referral process. The amount of relevant information provided on written referrals from other services was often brief and in some cases, only a name and diagnosis. Even when detailed referrals were provided, these were often inadequate because of the difficulties of capturing relevant information from long and complex medical and social histories on a referral form. The associated risks and resultant duplication of effort was a cause of frustration.

We've no background history.. if there was a risk four years agothey wouldn't tell us if there had been a risk. ..[you] just have to go out and see what's happening and sort of make your own assessment. So there's been a lot of duplication of work ...it has been difficult because it's time consuming and it's time that could be spent with three families rather than one. (AN 2)

Strengths and limitations

The multiple data sources enabled us to undertake a comprehensive detailed evaluation of the service. Whilst service activity data was generally well reported, some gaps in data collection and some recording anomalies, such as combined recording of age data for carers and PWD, limited our ability to report on these aspects.

Discussion

People with Dementia and their family carers living at home were the focus of a population intervention that was commissioned as an integrated service across health and social care. The strategic leadership of the five partners and the Clinical Commissioning Group was an important factor in negotiating the adoption of the Dementia UK model of Admiral Nursing with the addition of a bespoke local

Dementia Adviser role to facilitate the post diagnostic dementia support in the community. Joint commissioning, strategic intention and a commitment to a contextualised service model addressed many of the well documented problems associated with fragmented provision and a lack of joined up working (Bunn, Goodman, Pinkney, & Drennan, 2016; Care Quality Commission, 2016; Robinson et al., 2009).

The service provided long term care and support for 37.8% of the eligible population and their carers. In particular, it responded to an identified gap in services for those with vascular dementia and addressed the needs of families associated with managing a long term condition as indicated by findings from the carer experience surveys which reported benefit across all areas of care.

The service model described in this paper appears to be a novel approach. It contrasts with those approaches which have sought to develop integrated provision across a whole care pathway, for example by establishing structures and processes to facilitate closer working between a range of existing services across a care pathway (Kodner, 2006; Rosen et al., 2011) or by establishing extensive case management programmes where the case manager role is pivotal (Minkman, Ligthart, & Huijsman, 2009; Van Mierlo, Meiland, Van Hout, & Dröes, 2014; Vroomen et al., 2012). Our service model is more aligned to other integrated team approaches such as co-location of health and social care staff ((Brown, Tucker, & Domokos, 2003) and appointment of case managers (Bamford et al., 2014) and compares favourably with these other approaches in terms of the degree of joined up working.

The challenges that the evaluation highlighted arose from operating within multiple governance structures that have not previously shared organisational form, financial and administrative processes and shared ways of working. Rosen et al (2011) identified six integrative processes that can help coordinate care across team and organisational boundaries. Three of these, informational, clinical and normative processes merit consideration in terms of their long term consequences for this service.

The lack of information sharing arrangements created significant ongoing difficulties for the service. The amount of effort required to manage the risk arising from this is

not sustainable, particularly as there was high demand for the service. Given the multitude of health care provider arrangements that have evolved around the country, it is likely that other areas have encountered similar difficulties and achieved a satisfactory resolution of the problem. Identifying those services to understand the approaches they have used offers a practical way forward to resolving these issues.

The integrated service appeared to be successful in piloting a new skill mix of health and social care roles. The evaluation highlighted clear benefits of bringing AN and DA roles within a single workforce. Shared clinical processes including a single assessment and triage process together with seamless transfer between AN and DA caseloads enabled resources to be targeted in a timely and appropriate manner. Working within this structure fostered normative processes including shared values and created opportunities for knowledge sharing. These enabled the DA role in particular to develop and extend substantially beyond its original conceptualisation as a role that simply provided an identifiable point of contact and facilitated access to a range of local services (Clarke et al., 2013). Previous evaluations of Admiral Nursing services have highlighted ongoing difficulties resulting from the pressure to take on new cases and to hold caseloads too large for providing meaningful support (Bunn et al., 2016). In response to comparable problems in this service, there was a clear tendency for the DAs to take on complex caseloads, albeit with a social and community support remit. The training and development opportunities and the ongoing support afforded by the integrated structure enabled them to do so and enabled the service to manage demand using the CMS. This suggests that extending the DA role within this model of integrated service can provide a structure within which PWD and carers with a range of needs can be effectively aligned to the right level of support. There should be ongoing monitoring of DA role development to assess its impact and contribution to care provision and further consideration of their development needs as community workers.

Conclusion

This complex evaluation of a newly commissioned integrated service for people with dementia and their families in the community represents findings and analysis of process and outcome data for a 14 month pilot period. Short term funding for the pilot was achieved through integrated health and social care commissioning and

enabled a bespoke response to local need for post diagnostic dementia care and support. The integrated service was based on the configuration of ANs and DAs working within a strategic partnership arrangement that included NHS, social services and third sector provision. Contracting arrangements enabled the partnership of six organisations to generate the service and rapid development of operational processes enabled staff to respond to 37.8% of the eligible population and their families during the pilot.

This model of a fully integrated service for PWD offers a novel approach to addressing the problems of fragmented provision by enabling joined up working across health and social care. Further development of outcome metrics and satisfaction data would allow a greater health impact to be assessed, identifying the tangible benefits of the service to individual users and their families.

Funding

The project was funded as an independent evaluation by Making Space Ltd

Conflict of interest

No conflicts of interest have been declared.

Acknowledgements

We acknowledge the commitment and support of all the partner organisations and the service team to the evaluation.

References

Ahmadi-Abhari, S., Guzman-Castillo, M., Bandosz, P., Shipley, M. J., Muniz-Terrera, G., Singh-Manoux, A., . . . Brunner, E. J. (2017). Temporal trend in dementia incidence since 2002 and projections for prevalence in England and Wales to 2040: Modelling study. *BMJ (Clinical Research Ed.)*, 358, j2856.

Armitage, G. D., Suter, E., Oelke, N. D., & Adair, C. E. (2009). Health systems integration: State of the evidence. *International Journal of Integrated Care*, 9(2).

Bamford, C., Poole, M., Brittain, K., Chew-Graham, C., Fox, C., Iliffe, S., . . . Robinson, L. (2014). Understanding the challenges to implementing case

management for people with dementia in primary care in England: A qualitative study using normalization process theory. *BMC Health Services Research*, 14(1), 549.

Bodenheimer, T., & Berry-Millett, R. (2009). Care management of patients with complex health care needs. *Policy*, 1, 6.

Bodenheimer, T., Wagner, E. H., & Grumbach, K. (2002). Improving primary care for patients with chronic illness. *JAMA*, 288(14), 1775-1779.

Brown, L., Tucker, C., & Domokos, T. (2003). Evaluating the impact of integrated health and social care teams on older people living in the community. *Health & Social Care in the Community*, 11(2), 85-94.

Bunn, F., Goodman, C., Pinkney, E., & Drennan, V. M. (2016). Specialist nursing and community support for the carers of people with dementia living at home: An evidence synthesis. *Health & Social Care in the Community*, 24(1), 48-67.

Care Quality Commission. (2016). *Building bridges, breaking barriers: How care is integrated across health and social care and the impact on older people who use the service and their families and carers*. Care Quality Commission; London

Clarke, C., Keyes, S., Wilkinson, H., Alexjuk, J., Wilcockson, J., Robinson, L., . . . Corner, L. (2013). Healthbridge: The national evaluation of peer support networks and dementia advisers in implementation of the National Dementia Strategy for England. Dept of Health. Available at: <https://www.bl.uk/collection-items/healthbridge-the-national-evaluation-of-peer-support-networks-and-dementia-advisers-in-implementation-of-the-national-dementia-strategy-for-england-brief-report> (accessed on 27/4/2018)

Dept of Health. (2012). *Caring for the future: Reforming care and support*. HMSO; London

Goodwin, N., Smith, J., Davies, A., Perry, C., Rosen, R., Dixon, A., . . . Ham, C. (2011). A report to the Department of Health and the NHS future forum. *Integrated Care for Patients and Populations: Improving Outcomes by Working Together*. Available at: <https://www.kingsfund.org.uk/publications/integrated-care-patients-and-populations-improving-outcomes-working-together> (Accessed on 27/4/2018)

Ham, C., & Curry, N. (2011). *Integrated care: What is it? Does it work? What does it mean for the NHS?* Kings Fund; London: Available at https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/integrated-care-summary-chris-ham-sep11.pdf (Accessed on 27/4/2018)

Harrison Dening, K., Aldridge, Z., Pepper, A., Hodgkinson, C. (2017). Admiral nursing: Case management for families affected by dementia. *Nursing Standard*, 31(24), 42-50.

Jansen, L., Forbes, D. A., Markle-Reid, M., Hawranik, P., Kingston, D., Peacock, S., . . . Leipter, B. (2009). Formal care providers' perceptions of home-and community-based services: Informing dementia care quality. *Home Health Care Services Quarterly*, 28(1), 1-23.

Koch, T., Iliffe, S., Manthorpe, J., Stephens, B., Fox, C., Robinson, L., . . . Chew - Graham, C. (2012). The potential of case management for people with dementia: A commentary. *International Journal of Geriatric Psychiatry*, 27(12), 1305-1314.

Kodner, D. L. (2006). Whole - system approaches to health and social care partnerships for the frail elderly: An exploration of North American models and lessons. *Health & Social Care in the Community*, 14(5), 384-390.

Lloyd, J., & Wait, S. (2005). *Integrated care: A guide for policymakers*. Alliance for Health and the Future. Available at <http://www.ilcuk.org.uk/> (Accessed on 27/4/2018)

Minkman, M., Ligthart, S. A., & Huijsman, R. (2009). Integrated dementia care in the netherlands: A multiple case study of case management programmes. *Health & Social Care in the Community*, 17(5), 485-494.

NHS England. (2014). *Five year forward view*. Department of Health; London.

NHS England. (2017). *Integration and Better Care Fund planning requirements for 2017-19*. Dept of Health; London.

Office for National Statistics. (2015). *Statistical bulletin: Death registered in England and Wales (series DR) 2014*. Office for National Statistics; London:

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., . . . Salimkumar, D. (2014). *Dementia UK: An update. 2nd eEdition*. London: Alzheimers society. Available at

https://www.alzheimers.org.uk/downloads/download/1491/dementia_uk_update

(Accessed on 27/4/1018)

Robinson, A., Elder, J., Emden, C., Lea, E., Turner, P., & Vickers, J. (2009). Information pathways into dementia care services: Family carers have their say. *Dementia*, 8(1), 17-37.

Rosen, R., Mountford, J., Lewis, G., Lewis, R., Shand, J., & Shaw, S. (2011). *Integration in action: Four international case studies*. The Nuffield Trust. Available at <https://www.nuffieldtrust.org.uk/research/integration-in-action-four-international-case-studies> (Accessed on 27/4/2018)

Shaw, S., Rosen, R., & Rumbold, B. (2011). *What is integrated care?*The Nuffield Trust. Available at https://www.nuffieldtrust.org.uk/research/what-is-integrated-care?gclid=EAlalQobChMI9-r8wuPa2glVTr7tCh03RA12EAAYAiAAEgKX5fD_BwE (Accessed on 27/4/2018)

Spencer, L., Ritchie, J., O'Connor, W., Morrell, G., & Ormston, R. (2014). Analysis in practice. In J. Ritchie, J. Lewis, C. McNaughton Nicholls & R. Ormston (Eds.), *Qualitative research practice* (2nd ed., pp. 296-345). Thousand Oaks: Sage.

Van Mierlo, L. D., Meiland, F. J., Van Hout, H. P., & Dröes, R. (2014). Towards personalized integrated dementia care: A qualitative study into the implementation of different models of case management. *BMC Geriatrics*, 14(1), 84.

Vroomen, J. M., Van Mierlo, L. D., van de Ven, Peter M, Bosmans, J. E., van den Dungen, P., Meiland, F. J., . . . de Rooij, S. E. (2012). Comparing Dutch case management care models for people with dementia and their caregivers: The design of the COMPAS study. *BMC Health Services Research*, 12(1), 132.