

Improving effective integrated home support for people with dementia and their carers

KEY POINTS FROM THE RESEARCH

- A robust Fidelity Index tool and associated Service Template developed to assess the quality of home care for people with dementia had generally been seen by services as useful as a means of self-assessment, focusing attention on how services might be improved, in a setting where providing good service is evidently most difficult, which in turn makes engagement of services with research very challenging.
- While homecare is an important Government priority, services appeared to operate within significant 'structural' constraints, deriving from partnership issues and commissioning policies and practices, that appear to mitigate the application of many of the best practice standards set out in the Service Template. This includes disincentives for staff remaining in-post and developing in their role, as the result of a 'market place', based upon generally poor pay and conditions, and commissioning practices that can impact on the delivery of person-centred care.
- A significant finding of the research, and one that would benefit from further, more detailed work, is the area of partnership working, or collaboration, between home care services and their NHS colleagues. This was a recurrent theme in interviews with service managers,

and during conferences designed to explore the Service Template in more detail. While everyone would agree that good communication and cooperation between the different providers of health and social care are important, there would appear to be cultural and structural impediments to its realisation, that suggest the need for further research.

- Proper resourcing of services is essential and seeking more evidence, to weigh the relative importance of the key ingredients of good services and how they may best be combined, is crucial. The project team have continued to work to seek more such evidence and to 'validate' the Service Template, particularly with carers and those using the services.

BACKGROUND

This project aimed to create and test an evidence-based tool designed to allow services to critically self-assess the application of good practice standards in good home care for people with dementia (PWD).

The first stage of the project was to map from the literature the key ingredients, or enablers, that facilitate good care. The themes arising from this were then used, to develop an evidence-based 'Service Template' (shown in Table 1), listing items regarded as central to the delivery of good services. This process suggested

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Table 1. The Service Template

Theme	Elements of practice
1.Commissioning	Person-centred / outcome-based commissioning that focuses on the client, as opposed to the level of service, is deemed appropriate.
2.Integration, coordination and care management	'Joined-up care', i.e. activities between multiple stakeholders should be effectively coordinated.
3.Person- and relationship-centred care	The person with dementia and their carer are the explicit focus of the process, achieved by involving them and valuing their opinion.
4.Continuity of care	Allocation of the same care worker(s) to the client in order to build trusting relationships. The service should have sufficient numbers of staff to facilitate this.
5.Support for carers	Carers are integral to the support process and should therefore be considered as partners and service users in their own right.
6.Care planning	Effective, appropriate and realistic written plans of care that focus on the client's / carer's biography, reflect choice and promote (safe) independence. Plans should be accurate, fit for purpose and used as a tool for information, communication and monitoring.
7.Training	Staff working with PWD should have access to suitable dementia-care training and skill development appropriate to their role and responsibilities.
8.Support for staff	Staff should have access to a manager / supervisor who will assess and meet their training needs, monitor their performance and support them in their duties.
9.Flexible and responsive services	Flexibility of response – care available according to the needs of the client and their carer. Staff have the necessary time and flexibility to meet the needs of clients and carers.
10.Organisational factors	Provider facilitates person-centred care services via clear organisational (dementia oriented) policies. Procedures that reflect the elements of effective communication and person-centred care. Processes that facilitate cooperation and coordination of activities with care managers and other service providers. Adequate systems, resources, staff training and supervision. A culture that engages in audit and service improvement, including evidence that complaints are acted upon.

that a 'good' service is commissioned to be person-centred, rather than service-centred, is effectively planned and coordinated with other services, delivered consistently by sufficient numbers of well trained and supported staff, who are empowered to work in a flexible and responsive way, and which involves the principal carer.

Fidelity Index Self-Assessment

The second stage of the project involved translating the Service Template into a series of interlinked self-assessment questions (a Fidelity Index), and then testing the usefulness

of this tool with 32 managers of homecare for people with dementia from the public, private and voluntary sectors. The tool comprised 42 questions, each scored on a five-point (Never, Seldom, Half the Time, Usually, Always) scale. Service managers were also asked to distribute a questionnaire to key stakeholders (carers, staff and professionals), containing equivalent questions to those used in the Fidelity Index, for later comparison.

RESEARCH FINDINGS

For simplicity, we have chosen ten representative questions, linked directly to the Service

Table 2. Representative Fidelity Index questions matched to Service Template

Answers: 'Always' or 'Usually' and 'Agree' or 'Strongly agree'

Service Template	Question area	Manager (n=32)	Care worker (n=21)	Principal carer (n=17)
1.Commissioning	Can change the way that the service is provided or organised.	81.3%	85.7%	64.7%
2.Coordination and Care Management	Services for the client (e.g. district or nurses) are effectively coordinated.	81.3%	52.4%	35.30%
3.Person-centred care	Service takes into account the client's unique background and circumstances.	81.3%	100%	58.80%
4.Continuity of care	Allocation of same care workers for most visits.	90.7%	95.2%	35.2%
5.Support for the principal carer	Talking to the principal carer about their care and support needs.	84.4%	85.8%	23.5%
6.Care planning	The client has a written care plan that care workers follow.	65.6%	66.6%	52.9%
7.Training	Care workers are knowledgeable about the care needs of PWD.	93.8%	76.2%	41.2%
8.Support for staff	Workers have access to support from their managers when they need it.	96.9%	76.2%	58.8%
9.Flexible and responsive services	Time allocated to the client can be used flexibly and as needed.	46.9%	80.9%	58.8%
10.Organisational factors	The service's written policies and procedures are dementia friendly.	78.2%	76.2%	No equivalent question

Template, and showed the percentage of services answering 'Always' or 'Usually' to the ten questions and the percentage of care workers and principal carers 'Agreeing' or 'Strongly agreeing' to a similar range of questions (Table 2). From this, it appeared that those managing services provided positive responses to most questions within the Fidelity Index, i.e. they had generally indicated that a particular area of good practice 'Usually' or 'Always' happened within their service. The most noticeable exception related to the flexibility of the service, where under half indicated that their care workers would 'Always' or 'Usually' be able to use their time with the client flexibly. A similar pattern of positive responses emerged from care workers; with the exception of 'coordination and care management' (52% 'Agreeing' or 'Strongly

agreeing' that services are effectively coordinated). A possible explanation for this arose in the interviews with service managers, who suggested that the relationship between home care providers and some (district) nursing staff was not always good, leading to occasional operational issues for staff, such as being delayed between calls. Although only small numbers, positive responses from principal carers' were generally much lower across the range of questions, dipping to around 23% 'Agreeing' or 'Strongly agreeing' that someone from the service talked to them about their care needs. One independent sector manager explained that it was difficult to 'support' the principal carer, when the local authority was paying for a discrete client-focused service.

Interviews with service managers

Semi-structured interviews were conducted with service managers to understand how they had used the Fidelity Index tool, and the context within which it had been completed. It was evident that the service managers worked pragmatically and extremely hard to ensure the best possible service and outcomes for their clients. This often included a lot of (unpaid) networking with different stakeholders and occasionally, due to local need, delivering care to their clients in person. The principal message was that managing home care can be complex and challenging: *"Unless you work in the business, you don't understand the constraints, the financial constraints, the regulations we have to work by. It's hard work, you are swimming in treacle, basically"* (manager, medium size private sector organisation).

A significant finding suggested that different health and social care providers do not operate in a 'joined-up' manner, for example, there were several references to poor relationships between home care and district nursing staff: *"We find a lot of aggression from the NHS, not so much from the NHS as a Trust, but from the district nurses... They really, really don't like us for some reason..."* (private sector provider). Of equal significance and consistency were issues of communication and collaboration when clients required in-patient care: *"They're sending them home [from hospital] and then assuming that we will be going, but we don't even know that they've gone home"* (large private sector provider). These factors placed additional pressures upon clients and stakeholders, leading to inefficient and possibly unsafe service delivery.

Structural factors, over which the service could exercise little control, were consistent themes of the interviews, for example, the manager's ability to recruit and retain a suitable workforce: *"I take on eight care workers and lose four – each month"*. This meant that agencies: *"are always recruiting, because we never have enough carers"* (large private sector provider). Some attributed such problems to salary, where pay levels may be fixed for years by tendering arrangements: *"The poor pay... is the one thing that underlies all of our difficulties"* (large private sector provider). Tendering arrangements and

'minute-by-minute commissioning' tended to fix the price for care – in turn dictating the staffing and remuneration structure of the service, and the level of choice available to the client. *"It's all paid for by the electronic monitoring, so it's not a case of them actually choosing the kind of care, but with our private service users, we tailor the package to them"* (medium size private sector provider); *"We seem to get a lot of 15 minute calls now. By the time the carer has logged in, taken their coat off, you haven't got a lot of time left have you – and then when you've done what you've got to do, you have all of the notes to write..."* (private sector provider).

CONCLUSIONS AND FUTURE RESEARCH

The findings appear to comprise two distinct themes:

- (i) the generally positive messages regarding the Fidelity Index tool, its utility and application, juxtaposed with feedback from the stakeholder's equivalent questions; and
- (ii) contextual data, from the semi-structured interviews, suggesting a sector under significant pressure.

It was interesting that the care workers' assessments of the service were closely aligned with those of the service managers. However, assessments by the principal carers were consistently lower across the range of themes. This might suggest a disconnection between the providers' perspectives on their services and the actual experience of this key group. One of the Care Quality Commission's outcome measures is how providers assess and monitor the quality of services they deliver. A potentially useful aspect of the Fidelity Index tool was the use of these equivalent stakeholder questionnaires, with the theoretical potential to allow services to compare the manager's perception of the service with those of key stakeholders.

ABOUT THE STUDY

The study was conducted between November 2010 and May 2013 by researchers at the University of Nottingham. For further information contact Professor Rob Jones, University of Nottingham, Rob.jones@nottingham.ac.uk.