Provision of psychosocial interventions for people with mild to moderate dementia and their supporters following diagnosis: findings from a survey of memory services in Yorkshire and Humber region

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Executive Summary

In 2014/15 funding was received through the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care Yorkshire and Humber (NIHR CLAHRC YH) to survey the extent and nature of interventions being delivered to people in the post diagnostic period. Two systematic scoping reviews were also conducted in 2014/15 to determine the range and breadth of evidence-based interventions that have been designed and researched for people post diagnosis of dementia and those supporting them. The review findings are currently being updated and are not reported in this document.

The survey of memory services in the Yorkshire and Humber region of the UK aimed to elucidate current and future intended practice.

Survey results uncovered a high degree of variation in provision, some of which could be explained by different service structures and staffing configurations. It also identified some innovation in practice.

The survey findings served to illustrate how services need to identify and develop the capacity to provide interventions to people post diagnosis (both the person with a diagnosis and their family carers).

Service innovation within a whole system of treatment, care and support is recommended; thereby drawing upon social care organisations as well as health and including the charitable and not for profit sectors.

The views of current and proposed services from the perspectives of intended users should be prioritised (not undertaken as part of this survey and is a limitation).

Service providers are strongly encouraged to participate in research into psychosocial interventions being delivered through their services, as this will both drive up quality of existing provision and provide much needed evidence for service development.

Investment into the development and testing of psychosocial interventions for people following a diagnosis of dementia is insufficient to meet the needs of both service commissioners and providers. If people are to receive the range of services they require. Knowledge and evidence gaps also need closing.
Background

In 2009 the UK government mandated the establishment of memory clinics in each health locality so that people experiencing symptoms could access expert diagnosis and help. The drive for earlier and better diagnosis continues; emphasised in the Prime Ministers Challenge on dementia (Department of Health, 2012, 2015). The provision of psychosocial treatment and support in the post diagnosis period had lagged behind but this is now changing with growing awareness of the value that such interventions might provide to those in the earlier stages of the condition in addition to those supporting them (Kurz, Clare, & Lautenschlager, 2013; Moniz-Cook et al., 2008). Services are now required to implement evidence based interventions through memory services as recommended in the Royal College of Psychiatrists report (Hodge & Hailey, 2015) but the repertoire of recommended evidence based interventions is limited.

Psychosocial interventions may perform a range of functions in the post-diagnosis period for example supporting and enabling people adjust to their diagnosis, amelioration of the impact of the symptoms of dementia, enhancement of remaining cognitive capacity and improvement of day-to-day quality of life (Logsdon et al., 2010). The focus should be on enhancing and developing the skills and functions that remain, thereby retaining meaningful occupations, enabling social participation and fostering relationships (Brodaty & Donkin, 2009; Genoe & Dupuis, 2012; Innes, Page, & Cutler, 2015; Yuill & Hollis, 2011). Preservation of cognitive function for as long as possible is a further goal of certain psychosocial interventions such as cognitive rehabilitation (Moniz-Cook, Vernooij-Dassen, Woods, & Orrell, 2011). Therefore interventions provided in the post diagnosis period should meet specific needs that may emerge and change over time.

This study was conducted to obtain information about the range of psychosocial interventions currently provided through memory services in one region of the UK as well as what is being planned, using a postal/ internet survey to these services.
Methods

Ethical clearance was obtained through the University of Sheffield School of Health and Related Research.

Survey design was guided by best practice identified by McColl et al., (2001). Each of the study questions were addressed through a number of salient survey questions, identified through the evidence reviews and researcher awareness of current practice. Consideration was given to how questions were sequenced and worded including the best format for obtaining responses. Two survey designs were prepared; one postal and one online using Survey Monkey®. A limited pilot of the questionnaires was conducted with staff from one memory service prior to mail out.

Memory services (N = 22) and their clinical leads or services managers were identified for the Yorkshire and Humber region with the assistance of the Strategic Clinical Network for Dementia. Invitations to participate were distributed by post or by email. Invitation packs included: a letter of invitation, participant information sheet, a paper copy of the survey and web-links to the online version of the survey.

Data derived from completed surveys was entered into an SPSS data base and quality checked for errors before generating basic descriptive statistics. All reporting was anonymised.

Survey results

The survey elicited 15 responses (a response rate of 68%). One additional response had to be discounted due to the amount of missing data and was not included in the analysis.

Catchment populations of responding services reportedly ranged from 11,000 to 750,000 with estimated number of new diagnoses per year being between 120 and 3,000.

Service structures and organisation

In addition to providing memory clinics, six of the 15 services also included community teams for older people. Five services were multi-site (e.g. including clinics in primary care) four were single-site (hospital-based), one was peripatetic (moved around the patch) and the remaining incorporated a combination of model types. As might be expected differences were reported in the service offer from urban and rural settings with larger staff teams tending to work in city centre settings, with an associated more comprehensive service offer.

Staffing models

The majority of staffing structures incorporated specialist doctors, nurses, occupational therapists and psychologists with referrals to other health care professionals (e.g. physiotherapists and speech and language therapists) on an ad hoc basis. Two services employed dedicated dementia support workers as part of their team.
Post-diagnosis “service offer”
As can be seen from Table 3, intervention provision for people with dementia was highly variable. Cognitive Stimulation Therapy as recommended in NICE guidance (NICE, 2006) was the most frequently mentioned intervention. Counselling was most commonly offered on a dyad basis to both the person with a diagnosis of dementia and their supporter.

Routine offer of psychosocial Interventions
(Multiple responses possible)

<table>
<thead>
<tr>
<th>Psychosocial Intervention</th>
<th>Patient only</th>
<th>Patient &amp; Carer</th>
<th>Carer only</th>
<th>None</th>
<th>Not stated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counselling</td>
<td>2</td>
<td>6</td>
<td>1</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Cognitive Stimulation Therapy</td>
<td>5</td>
<td>1</td>
<td>N/A</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Group exercise</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>Group support and advice</td>
<td>2</td>
<td>8</td>
<td>0</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Assistive technologies</td>
<td>3</td>
<td>8</td>
<td>0</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Psycho-education Group</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>11</td>
<td>2</td>
</tr>
</tbody>
</table>

Other psychosocial interventions reportedly available through memory services for people post-diagnosis included: patient support groups, cognitive rehabilitation, life story work, reminiscence, individual cognitive stimulation therapy at home, provision of assistive technology, and occupational therapy (assisted living). Psycho-education groups were mentioned in the context of people with a diagnosis together with their carers.

Facilitators and Barriers to take up of interventions (from the perspectives of respondents)
The survey also requested information about the take up of psychosocial interventions being offered and what respondents considered were the main facilitators or barriers to take-up. The following were suggested as being factors that can encourage intervention take-up:

- Having a carer/supporter available
- Pressures of time and availability of carers/supporters to accompany
- Service accessibility and/or transport provision
- Time taken by staff to explain to discuss options and explain choices
- Tailoring services to individual need
- Provision of good quality written information
- Being given information to take home and digest
- Peer support networks
- Post clinic follow-up by service providers
- Psycho-education
- Personal need/circumstances (motivation)
- Referral by Alzheimer’s Society

Suggested barriers to take up of psychosocial interventions included:

- Transport/access difficulties
- Living alone/lack of carer support
- Lack of motivation
- Time and effort involved for carer
- Limited variety of interventions on offer
- Poor tailoring to individual needs
- Lack of reminders/prompts about appointments/groups
- Lack of information
- Social stigma
- Fear that others in group will have more severe dementia
- Refusal to accept condition
- Co-morbidities

**Non-NHS provision of psychosocial Interventions in the local area**

To attempt to identify the “whole system” of psychosocial treatment and support for people diagnosed with dementia, information was also requested about other providers of psychosocial interventions in the local area such as the charitable and private sectors, and the local authority. The Alzheimer’s Society was mentioned in the majority (14/22) responses. Other voluntary sector providers were also mentioned but the private sector was only mentioned once. Four responses reported provision through the local authority but it was not clear whether this was directed at people in the earlier stages of the condition. In one instance a neighbourhood network was reportedly providing support.

Those interventions provided by other organisations such as the charitable and not for profit sector were as follows (number of respondents in brackets): Dementia café (7), Patient education (3), Individual CST (2), maintenance CST (1), counselling (2), befriending (2), reminiscence, life history work, group support (2), art group (2), exercise/physical activity (2), a singing group (1), a gardening group (1), support workers (1), Jabadao (therapeutic dance) (1), circle dancing (1), day care/services/activities (5), social stimulation (1) and Singing for the Brain (1) although these may not have been targeted at people in the early to moderate stage of the disease.

**Future plans for expansion of provision of psychosocial interventions**

Ten responses described aiming to expand the current service offer to more patients. Nine services were planning to expand the range of psychosocial interventions they offered in the future to increase variety as listed below:
- Group cognitive stimulation therapy/individual cognitive stimulation therapy in the home/more cognitive stimulation sessions
- Cognitive stimulation therapy enabled through carers
- Cognitive rehabilitation
- Increased 1:1 post-diagnostic support (unclear whether for person with dementia, carer or the dyad)
- Facilitation of a self-run peer support network
- Self-management programme
- Education and support group
- Recovery college (a programme of short courses with support designed specifically to facilitate recovery from a range of mental health conditions e.g. http://www.southwestyorkshire.nhs.uk/about-us/recovery/kirklees/)
- Unspecified home-based interventions

“**Ideal World** provision from the perspectives of memory service providers”
Services were asked to give their views of what would be ideal provision through memory services if there were no resource constraints. The following were suggested:

- Routine counselling
- Memory groups/workshops
- Patient support groups
- Psycho-education
- Group and routine cognitive stimulation therapy
- Cognitive rehabilitation
- Crisis intervention
- Telecare/assistive technologies
- Peer support network
- Individual work on emotional wellbeing
- Support with social inclusion
- Complementary therapies
- General day activities
- Signposting and referral to other organisations

Associated issues mentioned in the context of ideal provision included the value of easy access to a case review specialist as needs change; longer case management and continuity; more individually tailored post diagnostic services, transport to/improved access to services and greater choice of peer support networks.

The following responses were provided in response to the question about ideal world provision through other organisations within a whole system of provision:-

“Same as now” (2), counselling (2), maintenance cognitive stimulation therapy (2), individual cognitive stimulation therapy in the patient’s home (2), reminiscence (2), exercise (2), Life History work (2), day services (2), social inclusion support (2), social/peer group support (2) self-help (1) emotional wellbeing support (1), and more generally: better “individually-tailored” activities.

Discussion

Survey findings illustrate the wide variety of service models for diagnosis and treatment and a developing mixed economy of service provision. However what appears to be largely ‘bottom up’ service development combined with a small range of recommended evidence based interventions (apart from cognitive stimulation therapy which is recommended in NICE guidelines (NICE, 2006) and limited policy direction means that there is no standard service offer for people post diagnosis.

The range of psychosocial interventions reported through the survey illustrates the limited investment into the development and research into such interventions to date. Given that this is a relatively recent area of service development this is not surprising. A small number of flagship services led by committed specialists could be identified and there was evidence of implementation of policy led guidance in practice; (for example peer support networks for
people with dementia as recommended in Living well with dementia (Department of Health, 2009).

The survey raises questions regarding the organisations that are best placed to deliver appropriate psychosocial interventions to people following diagnosis. Is it health or the charitable and/or private sectors? Arguments for and against different solutions can be identified. For example the resource implications for health service of this extension to their current remit set against service provision closer to the point of diagnosis could result in fewer individuals falling through the gap during service handover/referral. Furthermore continuity of care with known professionals and a familiar environment might be more desirable for people with memory impairment. The complexity of engaging with people post diagnosis can be inferred from the survey findings. The little researched area of readiness to engage is significant in determining take up what is offered and the likelihood or not of individuals falling through the net.

**Recommendations for practice**

Services need to develop the capacity to provide interventions to people post diagnosis (both the person with a diagnosis and their family carers). There can be a reluctance to engage by people post diagnosis for a variety of reasons; for example refusal to accept diagnosis with consequent implications for motivation. This in turn influences the uptake and effectiveness of interventions. Service innovation within a whole system with other providers is recommended, but consideration must be given to the views of services from the perspectives of intended users.

**Recommendations for psychosocial research**

The survey findings highlight the need for further research to develop and test new possibilities for psychosocial interventions (Kurz et al., 2013, Moniz-Cook, 2008) with emphasis upon engaging people living with dementia in co-design and testing.
References


