Dementia Adviser service:

Results of an evaluation of the Alzheimer's Society Pathfinder sites

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Abstract

Introduction

The National Dementia Strategy (2009) highlighted the need to 'enable easy access to care, support and advice following diagnosis'. In response to the emerging strategy, Alzheimer's Society set up several 'Pathfinder' Dementia Adviser services to pilot new service models. This report presents the findings of an evaluation of the pathfinder sites from the perspective of service users.

Aims

To investigate service user outcomes of the Society Pathfinder Dementia Adviser sites. To assess the experience of both people with dementia and carers in using the service in terms of access to, information quality, support received and operational data in terms of referral route and contact interactions. The findings from the project are intended to inform the wider development of Society services.

Method

Demographic data was collected from the Client Record System (CRS) a database developed specifically for the implementation and delivery of this service. A survey, measuring service users' perceptions of the service, was also developed for clients of the service. In-depth investigation of two clients, using region specific, information-oriented sampling, was also used to construct two case studies. CRS data was collected in the Pathfinder sites in Sheffield and Coventry between July 2009 and June 2010 and analysed for frequencies. The survey questionnaire was developed to measure service outcomes published in the Dementia Adviser service specification. The questionnaire was mailed to service users of the Pathfinder sites in July 2010 with a covering letter and stamped self-addressed return envelope; non-respondents were sent a follow up questionnaire. A separate questionnaire was sent to carers of people with dementia. The questionnaire was written, and survey data managed and analysed through the SNAP software program. Free text data from the survey was thematically analysed.

Results

The data set comprised 194 total clients of whom 108 are people with dementia, 32% of whom live on their own. The majority of clients were referred to the service through their local Memory service/clinic and no clients were referred by their GP. CRS data shows a gradual increase in number of referrals and contact interactions over time. Contact interactions mostly took place in the homes of service users and were on average over an hour in length. Case studies illustrate the variation in service delivery provided by the Dementia Adviser and the changing needs of people with dementia over time. The survey of clients achieved an overall response rate of 71%. There were few differences in the responses between people with dementia and carers. Key findings from the surveys include:

- Respondents reported a wide variety of information needs. Over half (57%) of people with dementia reported needing more information about dementia prior to receiving the Dementia Adviser service.
- Seventy-five percent of persons with dementia agreed that the information provided was relevant to them and 69% found it easy to understand.
- All respondents reported valuing the Dementia Adviser service with most people with dementia (57%) valuing the information about dementia and services. All respondents also appreciated the 'help' of the Dementia Adviser.
- Sixty-six percent of service users with dementia reported they would contact their Dementia Adviser in the future if they needed further information about dementia or dementia services.

Discussion

This study most importantly shows that people with dementia and carers valued the Dementia Adviser service and the information and support they received. Although most service users reported information needs relating to dementia, this study also highlighted the diversity and changing nature of service users' needs, the significant role of the Dementia Adviser to meet these needs and the breadth of knowledge required by a Dementia Adviser in able to support these clients to live well with dementia. A significant number of clients reported living alone suggesting the service is successful in reaching out to those most at risk of social isolation and possibly without the support network of a live-in carer. This evaluation suggests the Dementia Adviser service is building momentum over time but lack of GP referrals suggests more needs to be done in the future to fully integrate the service into the dementia care pathway.

Introduction

The publication of the National Dementia Strategy in 2009 aimed to ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care.(Department of Health, 2009) Objective 4 of the Strategy highlighted the need to 'enable easy access to care, support and advice following diagnosis.' The Strategy identified the development of a new service, the 'Dementia Adviser Service,' as the most effective way to meet this need. In response to the strategy Alzheimer's Society set up Pathfinder Dementia Adviser services in order to be able to pilot development methods and tools for the benefit of all Dementia Adviser services across the Society.

From September 2009 to April 2010 the Pathfinder Dementia Adviser sites were involved in the first phase of evaluation which focused on the barriers and facilitators to setting up the service. The results of this evaluation are published in two separate reports both of which are available on Arena.[1] The second phase of the evaluation was to gather and analyse service user perceptions of the Dementia Adviser service in order to feedback and influence service development and the sustainability of this innovative new service. This evaluation has three key aims.

- To establish basic demographic and service use data of our clients
- To measure service user perceptions of Dementia Adviser services in the three Pathfinder sites in Sheffield, Coventry and Greenwich
- The pilot of an evaluation tool which, following feedback from service users, will be revised and offered to all Alzheimer's Society Dementia Adviser services.

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[1] 'Barriers and facilitators to setting up the Dementia Adviser Service - Qualitative Analysis' and 'Barriers and facilitators to setting up the Dementia Adviser Service – CRS Analysis'.

Method

Client Record System

The Client Record System (CRS) was developed to record client data and information about interactions with the clients using Alzheimer's Society Dementia Adviser sites. The system is based on a secure cloud computing database from Salesforce.com. Dementia Advisers completed system training and were given a user guide setting out how to enter data, and were supported by the information management team.

Each client was given a unique ID automatically by the CRS. Basic demographic data was collected from consenting clients and included age, gender, living arrangements and ethnicity. Data about interactions with clients were recorded including whether the interaction was face-to-face, over the phone, or via email. It detailed how many people were involved and whether it was the person with dementia, carers and/or health professional. Also collected was a description of needs identified and length of time at each interaction. Data was collected from service inception in July 2009 and is included for analysis until the end of June 2010. CRS data were analysed for frequencies across both sites.

Questionnaire

The Quality and Evaluation team developed the questionnaire specifically for the Dementia Adviser service. The Dementia Adviser service specification was the key document in the development of the questionnaire as it informed both the expectations of the service model delivered but also the key outcomes expected of the service. The earlier evaluation undertaken to understand the barriers and facilitators to setting up the Dementia Adviser service, between September 2009 and March 2010, determined the realities of delivering the service as experienced by Dementia Advisers. A tool developed by the Personal Social Services Research Unit, as part of the Adult Social Care Outcomes Toolkit which measures service user perception of information and advice services, was also used to align the questionnaire to other information specific services.[2]

A draft questionnaire was analysed during a workshop with Pathfinder Dementia Adviser staff and managers. The changes made in this workshop, including a carer-specific questionnaire[3], led to the final two questionnaires. The questionnaire was written, data managed and analysed through the SNAP software program.

The questionnaire was sent out to all clients, past and current, of the Pathfinder sites since their inception; services had been running for approximately one year. All persons with dementia were sent a questionnaire and those carers who were living with the person they care for were sent a separate carer's questionnaire.

Although initially the questionnaire was sent to clients of the Greenwich Pathfinder site, due to inconsistencies in the data provided the site was later removed from the evaluation. Therefore data from the CRS describing the Greenwich Dementia Adviser service has also been removed. The questionnaire was sent out in July 2010 with a covering letter and stamped self-addressed return envelope. Non-respondents were sent a follow up questionnaire four weeks later. All data reported is for Pathfinder sites in Sheffield and Coventry.

Case studies

In-depth investigation of two clients' data, using region specific, information-oriented sampling, was used to construct the case studies. Data collected included; CRS demographic data, longitudinal case notes collected by the Dementia Adviser and returned questionnaire data. The case studies are reported in the results as a narrative describing service provision and their clients' experience where possible.

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[2] This tool has not yet been published by the PSSRU: http://www.pssru.ac.uk/ascot/index.php

[3] It was felt that by giving carers their own questionnaire to complete they would appreciate the opportunity to have their voice heard, but also to ensure that they were aware that the expectation was for the person with dementia to complete their own questionnaire.

Results

Client Record System

Table 1 shows the number of clients (194), both people with dementia and carers, registered on the CRS. Table 1 also shows the region, gender of clients and living status of people with dementia. Results show that 115 clients (59%) are female and 32% of people with dementia who receive the service live on their own. The data appears to suggest that approximately 20% of people with dementia do not have a carer. It is possible some clients may have more than one carer recorded on the CRS, and therefore the actual figure of people with dementia without carers could be even higher. Carers of people with dementia are also predominantly female (69%).

Table 1. Type, gender and living status of people with dementia (July 2009 – June 2010)

	People with dementia			
	Living alone	Living with others	Not recorded	Carers
Coventry				
Male	4	20	0	14
Female	11	17	1	26
Sheffield				
Male	5	22	1	13
Female	15	10	2	33
Total	**35**	**69**	**4**	**86**

Table 2 shows the age and ethnicity of people with dementia. Due to the relatively small numbers of people with dementia included in the analysis (n=108), age and ethnicity have been grouped. Ethnicity has been grouped as White (includes White British – Northern Irish, Scottish, English, Welsh) or Not Recorded. Most clients (64%) were aged between 65-84 years although a proportion were aged over 85. Only a small number of clients (4%) were aged 64 years or less although the ages of 18 clients were not recorded on the CRS. The ethnicity of over half of people with dementia was not recorded on the CRS database.

Table 2. Age and ethnicity of people with dementia (July 2009 – June 2010)

	Ethnicity		
	White	Not recorded	Total
Age (Years)			
64 and under	2	3	4
65 – 84	43	26	69
85 and over	7	9	16
Not recorded	1	17	18

Table 3 shows the referral route according to site.[4] The majority of clients are referred to the service via their Memory service followed by the Mental Health Trust or referral by a carer, family member or friend. Of the 'other' responses (12) that were detailed in a free text option 10 were referred to the Dementia Adviser by other Alzheimer's Society services.

Table 3. Referral route to the service for people with dementia (July 2009 – June 2010)

	Coventry	Sheffield	Total
Local Memory Clinic	31	15	46
Mental Health Trust	27	1	28
Carer, family member or friend	7	8	15
Other (described in free text)	4	8	12
Voluntary sector	6	0	6
Occupational therapist	4	1	5
Self referral	1	4	5
Other NHS	4	1	5
Housing association	0	2	2
GP	0	0	0
Community Psychiatric Nurse	0	0	0
Social Services	0	0	0
Admiral Nurse	0	0	0
Care home	0	0	0
Person with dementia	0	0	0
Not recorded	2	14	16

Table 4 details the total number of referrals to the service from service inception to June 2010 according to month and year. The data suggests a slow steady intake of clients since service inception with a clear down turn in number of referrals in traditional holiday periods.

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[4] The number of referrals is larger than the number of clients who 'use' the service as clients are referred before they meet with the Dementia Adviser and not all clients referred to the service actually go on to use service.

Table 4. Number of referrals to the service by year and month (July 2009 – June 2010)

	Coventry	Sheffield	Total
2009			
July	4	5	9
August	3	13	16
September	2	10	12
October	8	8	16
November	5	5	10
December	4	-	4
2010			
January	9	-	9
February	12	5	17
March	11	4	15
April	14	4	18
May	7	1	8
June	7	-	7

Table 5 details the number and type of contact interactions from service inception to July 2010. Dementia Advisers are most likely to visit clients in their homes or to contact them via telephone. A small number of contact interactions are not recorded.

Table 5. Number and type of contact interactions (July 2009 – June 2010)

	2009						**2010**						
	Jul	**Aug**	**Sep**	**Oct**	**Nov**	**Dec**	**Jan**	**Feb**	**Mar**	**Apr**	**May**	**Jun**	**Total**
One-on-one meetings													
At client's homes	7	13	15	20	22	12	15	19	29	19	10	25	206
At Society offices	0	1	10	5	12	1	1	2	3	3	2	2	42
Elsewhere	1	0	2	1	0	0	1	3	3	2	0	2	15
Phone call	3	1	5	8	15	7	15	19	15	16	8	18	130
Other (letters, email)	0	0	2	0	0	0	0	3	1	0	1	23	22
Not recorded	2	3	1	2	4	1	1	2	7	1	11	5	40

Table 6 details the average length of time of contact interactions from service inception to July 2010.

Table 6. Average length of time (minutes) of contact interactions (July 2009-June 2010)

	2009						**2010**						
	Jul	**Aug**	**Sep**	**Oct**	**Nov**	**Dec**	**Jan**	**Feb**	**Mar**	**Apr**	**May**	**Jun**	**Total**
One-on-one meetings													
At client's home	84	61	67	63	71	75	71	68	74	66	84	62	69
At Society offices	0	60	75	60	50	70	20	33	53	65	90	35	58
Elsewhere	15	0	23	20	0	0	60	62	32	120	0	105	58
Phone call	9	10	11	11	12	20	14	9	15	9	13	8	12
Other (letters, email)	0	0	0	0	0	0	0	4	60	0	360	6	19
Not recorded	0	38	90	75	38	20	15	120	86	60	100	96	76

Face to face meetings with clients were around one hour although slightly longer if the meeting was in the client's home. Phone calls were 12 minutes and other interactions including letters and emails were 19 minutes long on average. The average length of time in minutes of those interactions where the type was not recorded is 76 minutes.

Questionnaire

The questionnaire was posted to 163 clients; 105 were people with dementia and 58 were to carers who lived at the same address as the person they cared for. An overall response rate of 71% was achieved. The response rate is detailed in Table 7.

Table 7. Response rate (People with dementia and carers)[5]

	Coventry	Sheffield	Total
People with dementia living alone	9/20 (45%)	13/25 (52%)	22/45 (49%)
People with dementia living with a carer	25/31 (81%)	23/29 (79%)	48/60 (80%)
Carers living with people with dementia	25/31 (81%)	21/27 (78%)	46/58 (79%)
Total	59/82 (72%)	57/81 (70%)	116/163 (71%)

Overall 70 responses were received regarding people with dementia. Of these responses, 62 returned questionnaires; 19 from persons living alone and 43 from persons living with carers. Eight questionnaires were not returned by service users due to individual reasons including 'deceased' and 'moved to residential setting'. Twelve questionnaires from people with dementia were received following the second mail out.

Some 46 responses were received from carers, 43 of which were returned questionnaires. Eleven questionnaires were received from carers following the second mail out.

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[5] The number of clients sent the questionnaire is slightly more than the number of clients on the CRS even though the dates extracted were the same. As the CRS data was not extracted until November 2010 the numbers are slightly different likely due to the timing of data entry done by Dementia Advisers.

People with dementia

Fifty-nine persons with dementia (95.2%) completed the question asking how old they are. Respondents were aged between 62 and 89 (mean: 77). Fifty-six respondents completed the question asking respondents to detail their ethnicity as an open response questions. Most respondents recorded their ethnicity as 'British' or 'English' (61%). When asked if they live on their own, eleven (18%) of respondents answered yes and 48 (77%) respondents reported 'no'.

Eighteen (29%) respondents reported completing the questionnaire themselves, 36 (58%) reported completing the questionnaire with the help of a family member, carer or friend, four (6.5%) reported completing the questionnaire with the help of a professional care or support worker, and four (6.5%) respondents did not complete this question.

People with dementia were asked to identify their information needs before they had been in contact with the Dementia Adviser (Table 8). Respondents could tick all options that applied to them. The majority of respondents (57%) chose 'Dementia' although many 'did not know they needed any information' (38%). 'Support to do everyday things' (26%), 'Support to do the things I enjoy' (24%) as well as information about 'Family/carer' (24%) were identified by a number of respondents. Three respondents identified 'other'. These included; questioning whether they would be able to support themselves, denial of dementia therefore 'no need for information' and 'no need for help only information'.

Table 8. Information needs before referral to the Dementia Adviser service

Information needs	Responses
No reply	6 (10%)
Dementia	35 (57%)
I did not know I needed any information	24 (38%)
Support with everyday things	16 (26%)
Support to do the things I enjoy	15 (24%)
Family/Carer	15 (24%)
Legal rights	13 (21%)
Driving	13 (21%)
Health	11 (18%)
Money	8 (13%)
Housing	3 (5%)
Other	3 (5%)

People with dementia were asked about the information and support available to them before meeting the Dementia Adviser (Table 9). Twenty-four (39 %) respondents either 'strongly disagreed' or 'disagreed' that they knew where to go to get help. Most respondents (55 %) either 'strongly agreed' or 'agreed' that they were concerned before they spoke with the Dementia Adviser. Ninety percent 'strongly agreed' or 'agreed' that the Dementia Adviser met with them in a place that was convenient to them.

Table 9. Before meeting the Dementia Adviser

	No reply	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
Before I spoke with the Dementia Adviser I knew where to go to get help	5 (8 %)	9 (15 %)	7 (11 %)	17 (27 %)	16 (26 %)	8 (13 %)
Before I spoke with the Dementia Adviser I was concerned	6 (10 %)	12 (19 %)	22 (36 %)	10 (16 %)	8 (13 %)	4 (7 %)
The Dementia Adviser spoke with me in a place that was convenient for me	5 (8 %)	30 (48 %)	26 (42 %)	-	-	1 (2 %)

People with dementia were asked how many times they had met with their Dementia Adviser. The majority of respondents (58 %) reported meeting their Dementia Adviser two to four times. Thirteen percent had seen their Dementia Adviser once and 15 % had met with their Dementia Adviser more than four times. Four (7 %) people were 'not sure' and five (8 %) did not reply.

Respondents were asked about their experiences of meeting with the Dementia Adviser and how they felt during this process (Table 10). Most respondents (85 %) agreed that they felt listened to and respected by the Dementia Adviser and most respondents (82 %) felt involved when they spoke with the Dementia Adviser. Respondents were mixed in their response to the question asking them whether or not they felt encouraged to make decisions by the Dementia Adviser. Fifty three percent disagreed with the statement and felt they were encouraged to make decisions, 19 % were not sure and 14 % felt they were not encouraged to make decisions.

Table 10. Perspectives of meetings with the Dementia Adviser

	No reply	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
I felt listened to and respected by the Dementia Adviser	6 (10 %)	28 (45 %)	25 (40 %)	2 (3 %)	-	1 (2 %)
I felt involved when I spoke with the Dementia Adviser	6 (10 %)	26 (42 %)	25 (40 %)	4 (7 %)	-	1 (2 %)
I did not feel encouraged by the Dementia Adviser to make decisions	8 (13 %)	1 (2 %)	8 (13 %)	12 (19 %)	20 (32 %)	13 (21 %)

Respondents were also asked to clarify their thoughts on the quality of information provided by the Dementia Advisers (Table 11). Seventy four percent of respondents 'strongly agreed' or 'agreed' that the information provided by the Society was relevant to them and 69 % felt the information was easy to understand. Seventy four percent 'strongly agreed' or 'agreed' that the Dementia Adviser helped them to access other Alzheimer's Society services and 66 % felt the Dementia Adviser helped them to access information or services from other organisations. Some respondents (33 %) either 'strongly agreed' or 'agreed' that they needed more help to follow up on the information provided. Ten percent of respondents tried to follow the information but came to a dead end.

Table 11. Perspectives of the quality of information provided by Dementia Advisers

	No reply	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
The information the Dementia Adviser provided was relevant to me	10 (16 %)	19 (31 %)	27 (44 %)	6 (10 %)	-	-
The information provided was easy to understand	10 (16 %)	12 (19 %)	31 (50 %)	9 (15 %)	-	-
The Dementia Adviser helped me to access information / services from the Alzheimer's Society	12 (19 %)	16 (26 %)	30 (48 %)	4 (7 %)	-	-
The Dementia Adviser helped me to access information / services from other organisations	11 (18 %)	14 (23 %)	27 (44 %)	10 (16 %)	1 (2 %)	-
I needed more help to follow up on the information I was given	10 (16 %)	5 (8 %)	16 (26 %)	14 (23 %)	14 (23 %)	2 (3 %)
I tried to follow the information but I came to a dead end	10 (16 %)	2 (3 %)	4 (7 %)	17 (27 %)	16 (26 %)	12 (19 %)

Respondents were asked to indicate what two things they valued most about the service (Table 12). The 'knowledge someone is on my side' and 'information about dementia and services' were each identified by approximately half of respondents. The 'trusted friendship', the 'emotional support' and 'the practical help I receive' were each identified by 21 -26 % of respondents. One respondent chose the option 'other' as they 'only had one visit so too early to say.' No respondents reported that they did not value the service.

Table 12. Breakdown of the most valued aspects of the Dementia Adviser service

	Responses
No reply	6 (10 %)
The information about dementia and services	35 (57 %)
The knowledge someone is on my side	29 (47 %)
The practical help I receive	16 (26 %)
The emotional support	15 (24 %)
The trusted friendship	13 (21 %)
Nothing, I don't value the service	0 (0 %)
Other	1 (2 %)

Respondents were asked to identify who they would consult in the future if they had a question about dementia or dementia services and could tick all that applied (Table 13). Two thirds of respondents identified the Dementia Adviser. Approximately half of respondents identified each of their 'Carer' or a 'Family member.' Between 15 – 24 % of respondents also identified 'friend', 'Social care professional' or 'Health professional'. Five percent of respondents were 'not sure' who they would consult and one respondent suggested 'No one'.

Table 13. Breakdown of those most likely to be consulted about Dementia

	Responses
No reply	6 (10 %)
Dementia Adviser	41 (66 %)
Your carer	32 (52 %)
A family member	31 (50 %)
Health professional	15 (24 %)
Social care professional	11 (18 %)
A friend	9 (15 %)
Not sure	3 (5 %)
Internet	2 (3 %)
No one	1 (2 %)
Other	0 (0 %)

People with dementia were invited to express further comments about the service in a free text field. Twenty eight respondents (45 %) chose to leave a comment; 14 of these could be categorised as positive, while only 1 as negative, and the remaining 13 as neither positive nor negative.

Of the positive comments, the most frequent identifiable themes (n = 8) referred to the 'help' given by Dementia Advisers. For example, one respondent wrote:

> *'I just called in for information and was offered a meeting straight away. We were really welcomed and helped through the process of diagnosis with Neurology. It also helped that they know the people involved'*

There were two positive themes that were raised four times; one was that Dementia Advisers provide 'support', the other that they provide 'information'. One respondent wrote:

> *'I found the Dementia Advisor Service very useful in giving the relevant help, support and information at the time required'*

Other positive themes included that the Dementia Adviser was 'friendly/easy to talk to' (n = 3)

> *'I find it easy to talk to [Dementia Adviser named]. I find she is very thoughtful. I can trust and rely on her. For her age she is extremely mature. Nothing is too much trouble whatever needed'*

'understanding' (n = 2):

> *'I always feel better in myself after the adviser has left. Because after discussing things with her, her explaining, her help and understanding makes me feel better in myself that day'*

'good all round' (n = 2):

> *'Nothing but praise for this service'*

Responses that were neither positive nor negative were often an explanation for why the respondent was not using the service at present (n=5). Other comments; simply stating that they have nothing to add (n= 2) and information to add detail to specific questions (n= 1). The only negative comment was by a respondent who had received little contact:

> *'The Dementia Advisor resigned from her post at least 6 months ago and there has been no contact from a replacement adviser since that happened'*

A further 12 comments (19%) were made by people with dementia about the questionnaire. Of these, five were positive and seven negative. In terms of the positive feedback, one respondent found the faces useful, while four other positive comments reflected that the questionnaire was easy to understand. The negative comments all related to respondents finding the questionnaire difficult. Six of these were made by people with dementia and one was a comment added by a carer. One person with dementia detailed the questions they had difficulty with. They found Q8c "I did not feel encouraged by the Dementia Adviser to make decisions" difficult to understand, and concerning Q11, that asks what they value about the Dementia Adviser, the respondent wanted to tick more than two boxes. A carer also added in the general comments box that they thought that Q8 was confusing.

Carers

Carers were asked to identify the information needs of the person they cared for before they had been in contact with the Dementia Adviser (Table 14). Respondents could tick all options that applied. The majority of responses (67 %) were for 'Dementia'. There were some responses for 'They did not know they needed any information' (33 %) and 'Support to do everyday things' (30 %). There were two responses for 'Other'; 'Outdoor activities' and 'Already knew from attending the care group sessions.'

Table 14. Information needs of the person they care for

Information needs	Responses
No reply	3 (7 %)
Dementia	29 (67 %)
They did not know they needed any information	14 (33 %)
Support with everyday things	13 (30 %)
Driving	10 (23 %)
Family/Carer	9 (21 %)
Support to do the things they enjoy	9 (21 %)
Health	8 (19 %)
Legal rights	7 (16 %)
Money	5 (12 %)
Housing	2 (5 %)
Other	2 (2 %)

Carers were asked to respond to statements about the knowledge and feelings of the person they care for before they met with the Dementia Adviser (Table 15). Seventeen respondents (40 %) either 'strongly disagreed' or 'disagreed' that the person they care for knew where to go to get help and 26 % reported being 'not sure'. Most respondents (60 %) either 'strongly agreed' or 'agreed' that the person they care for was concerned before they spoke with the Dementia Adviser.

Table 15. Carer perception of the information and support available to the person prior to them meeting with the Dementia Adviser

	No reply	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
Before the person I care for spoke with the Dementia Adviser they knew where to go to get help	5 (12 %)	3 (7 %)	6 (14 %)	12 (28 %)	11 (26 %)	6 (14 %)
Before the person I care for spoke with the Dementia Adviser they were concerned	4 (9 %)	8 (19 %)	18 (42 %)	8 (19 %)	5 (12 %)	-

Carers were asked how many times the person they care for had met with the Dementia Adviser. The majority of respondents (58 %) reported the person they care for had met the Dementia Adviser between two and four times. Twenty percent reported the person they care for had met with the Dementia Adviser more than four times and 14 % had seen their Dementia Adviser once. Three (7 %) did not reply.

Carers were asked about how the person they care for feels during sessions with the Dementia Adviser (Table 16). Most respondents (86 %) agreed that the person they care for felt listened to and respected by the Dementia Adviser. Carers were more mixed in their answer to the question asking them whether the person they care for felt encouraged to make decisions by the Dementia Adviser. Sixty-three percent disagreed with the statement and felt the person they care for were encouraged to make decisions, 9 % were not sure and 11 % felt the person they care for were not encouraged to make decisions.

Table 16. Carers view of the feelings of the person they care for during meetings with the Dementia Adviser

	No reply	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
The person I care for felt listened to and respected by the Dementia Adviser	3 (7 %)	16 (37 %)	21 (49 %)	2 (5 %)	1 (2 %)	-
The person I care for did not feel encouraged by the Dementia Adviser to make decisions	7 (16 %)	1 (2 %)	4 (9 %)	4 (9 %)	18 (42 %)	9 (21 %)

Carers were also asked to report on the quality of information provided by the Dementia Advisers (Table 17). Eighty one percent of respondents 'strongly agreed' or 'agreed' that the information provided by the Society was relevant to the person they care for. Eighty six percent of respondents 'strongly agreed or agreed' that the Dementia Adviser helped them to access other information or services. Some respondents (35 %) either 'strongly agreed' or 'agreed' that the person they care for needed more help to follow up on the information provided.

Table 17. Carers perception of the quality of information

	No reply	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
The information the Dementia Adviser provided was relevant to the person I care for	5 (12 %)	15 (35 %)	20 (47 %)	3 (7 %)	-	-
The Dementia Adviser helped the person I care for to access information / services	3 (7 %)	17 (40 %)	20 (47 %	2 (5 %)	1 (2 %)	-
The person I care for needed more help to follow up on the information they was given	8 (19 %)	4 (9 %)	11 (26 %)	10 (23 %)	9 (21 %)	1 (2 %)

Carers were asked to identify who the person they care for would consult in the future if they had a question about dementia or dementia services and could tick all that applied (Table 18). Most respondents identified the Dementia Adviser. Approximately one third of respondents identified each of 'carer' 'family member' or 'health professional.' Seven percent of respondents were 'not sure' who the person they care for would consult and 7 % thought they would consult 'no one.' Three respondents choose the 'other' option. Two respondents specified 'me' and one respondent wrote 'leaves everything to me.'

Table 18. Breakdown of who carers think are most likely to be consulted about dementia

	Responses
No reply	5 (12%)
Dementia Adviser	24 (56%)
Carers	15 (35%)
A family member	14 (32%)
Health professional	14 (32%)
Social care professional	5 (12%)
A friend	4 (9%)
Not sure	3 (7%)
Internet	3 (7%)
No one	3 (7%)
Other	3 (7%)

From the 43 questionnaires received from carers, 27 provided additional comments in the space provided at the end of the questionnaire. Fourteen of these comments could be described as positive, five negative, and the remaining nine neither positive nor negative.

The most frequent identifiable theme in the positive feedback (n = 9), was as with the comments from people with dementia, that the Dementia Adviser was a 'help/helpful'. One person wrote:

> *'Without the help of the dementia advice [sic] I would have struggled to get the help and support I now have the benefit of each week'*

Other positive identifiable themes each with three comments were that the Dementia Adviser is 'always there':

> *'I do not know what I would have done without our advisor. She is always there if we need help and does all she can to make life easier'*

Provides 'advice/information':

> *'The Dementia Advisor was very helpful and gave me information as to where to ask for help when the necessity occurs'*

Is 'good all round':

> *'The Advisers I have met have been excellent in every way'*

Two carers' comments related to the fact that they felt that they did not have to cope 'alone'. While one further comment related to the fact that the Dementia

Adviser was good at helping the person with dementia to understand information. They wrote:

> *'The person I care for feels better in himself when the advisor explains things to him and is relieved to have someone who cares. He has a good relationship with her when she explains things to him. And tries to make him understand'*

Of the feedback that was neither positive nor negative, five comments provided an explanation for completing the questionnaire in a particular way, such as they were not sure how to answer questions or had given some negative answers. The other four such comments were to inform the Society about changes in the condition of the person they are caring for, such as they were now deceased.

Of the five negative comments, three related to the service received. They were as follows:

> *'Good contact with Alz Cafe and Quest groups. Not sure if Dementia Support Services are still operating as saw advisor once'*
>
> *'As my wife does not fit into the standard model of Alzheimer patient, the adviser felt that she couldn't help any more (that's the conclusion I got)'*
>
> *'I feel as my mum's carer, I need more knowledge and understanding to help me with her illness. I would prefer one to one basis a person could give me and the support needed'*

One of the other comments was a suggestion on how to save resources:

> *'Was it necessary to use a first class stamp? I am returning one to you!'*

Case studies

Case study A

Mr Brook is a 73 year old man and he lives with his wife/carer. Before he visited the Dementia Adviser (DA) he was not sure where to go for help and admitted feeling concerned. He particularly wanted some more information about dementia but also about his legal rights. He was referred to the Dementia Adviser service by his Consultant Psychiatrist who had recently diagnosed him with Alzheimer's disease. The DA set up a meeting with himself and his wife in early March 2010. They discussed his diagnosis, general health and care needs as well as some of his background and general interests for about two hours. The DA recommended the couple attend the local dementia café for more information about dementia and it was agreed that the DA would continue to provide support.

Towards the end of April the DA again visited Mr Brook in his home for just over an hour. The couple had really enjoyed going to the Dementia Café and asked about any other similar events. The DA signposted them to a Dementia Information group that meets monthly in the area provided by an external organisation. Mr Brook was interested in more information about a Lasting Power of Attorney (LPA) so the DA gave them a copy of the form so they could see what was involved. Mr Brook agreed that the information the DA provided was relevant, easy to understand and had helped them access services both within the Society and externally. He also felt listened to, involved and encouraged to make decisions by the Dementia Adviser.

The DA visited again in June for an hour and a half and found things had changed somewhat. Mr Brook was suffering from a number of new and recurring medical problems, including dizziness. He had also felt a loss of confidence and motivation and was sleeping a lot. The DA referred them to an Adult Exercise Class and a Social Group run by Age Concern as well as a 'Ring and ride' company to help with transport. The DA mentioned the possibility of seeing an Alzheimer's Society 'Leisure worker' once a week to help motivate him back into his routine but his wife felt she could do this. Mr Brook was also concerned about LPA and spoke at length about this to the DA. Mr Brook and his wife now need to talk about LPAs between themselves and see their solicitor.

Mr Brook felt the two things that he valued most about the DA service were the provision of information about dementia and the emotional support he received. In his own words Mr Brook wrote about the service:

> *'I always feel better in myself after the Adviser has left. Because after discussing things with her, her explaining, her help and understanding makes me feel better in myself that day.'*

Case Study B

Mrs Morrison is 79 years old and lives with her husband who is also her carer. Mrs Morrison was referred to the service by her local Memory service. Before she spoke with the Dementia Adviser (DA) she did not know if she needed any information although she did feel some information about dementia and support with everyday things would be useful. The DA first visited Mrs Morrison in early March in her home for 45 minutes but neither she nor her carer had any concerns or questions at the time. Both she and the DA felt a visit in the future would be beneficial.

The DA met with Mrs Morrison and her carer in August and September in 2009. They are waiting on the results of an Attendance Allowance claim which the DA helped them to complete earlier. The DA provided them with information to alleviate Mrs Morrison's concerns of 'passing' dementia on to her children which Mrs Morrison found very helpful.

In June 2010 the DA met with Mrs Morrison and her husband at home for one hour. Mrs Morrison reported difficulties getting in and out of the bath, and found the stairs difficult. The DA advised them to contact Social Services and gave them the telephone number. The Morrisons also expressed interest in social opportunities and respite care for Mr Morrison. The DA encouraged them to attend the Dementia Café in their area. Mrs Morrison reported valuing the information about dementia and services and the emotional support she received from her DA. She reported that the Dementia Adviser was *'easy to talk to and doesn't make you feel foolish.'*

In September the DA visited the Morrisons at home to discuss their options after the Council turned them down for bathroom adaptations and a stair lift. Mr Morrison was very reluctant to move, concerned about the safety of known sheltered housing areas. After consulting with the DA, the couple decided to appeal on the grounds of insufficient weight given to Mrs Morrison's dementia. In the interim the DA suggested having a Social Services Assessment for Mrs Morrison's personal care which was becoming too much for her husband without the adaptations. At this time the DA sent a letter asking for further clarification of the details of the refusal by the Council in order to appeal and also to Mrs Morrison's Consultant in order to gain his support.

The DA sent the appeal letter on behalf of Mrs Morrison and her husband in mid September. The DA set out the key points of the appeal; 1) The difficulties of re-housing and 2) The possible policy discrimination.

In mid-October 2009 the DA met with the Council Assessor and Mrs Morrison's family at which time the points of the appeal letter were debated. The next day the Council stated they would install all adaptations within three to four months time. The family of Mr and Mrs Morrison emailed their DA to say thank you and felt they would not have got that far without the help of the Society.

Discussion

Data extracted from the CRS shows the number and type of clients the service has reached in the last year in both the Coventry and Sheffield Pathfinder sites. Most striking is the number of clients who live on their own, most of whom are female. While these demographics are reflective of the older population in general (Office for National Statistics and Department for Work and Pensions, 2005) it is an important reminder that many people with dementia do not have a live-in carer and some may not have an informal carer at all. As current government policy is focused on preventing unnecessary hospital admission, supporting early discharge and reduction or delay of the need for long-term residential care (Department of Health, 2010), the number of people with dementia living in the community will continue to grow; the Dementia Strategy estimates the number of people with dementia in the UK will double to 1.4 million in the next 30 years. (Department of Health, 2009) It is promising that the Dementia Adviser service is reaching those who are living alone, who may be at most risk of social isolation and who may need added support to access information and services.(Miranda-Castillo *et al.* 2010b)

The CRS data outlines clearly the referral routes for clients of the two Pathfinder sites. In both Pathfinder sites the largest number of referrals came from the local memory clinic with carers, family members or friends also making a number of referrals. Interestingly, there a number of regional differences; this highlights the necessity of a unique awareness raising strategy in each region, depending on the services available. Additionally, there were no referrals from GPs in either area. This is an interesting finding particularly in light of the recent proposed changes to the commissioning of health services outlined in the White Paper.(Department of Health, 2010) The current Government is planning to devolve power and responsibility for commissioning services from Primary Care Trusts to GPs and their practice teams working in consortia.(Department of Health, 2010) How the impact of these changes will be felt by new services like the Dementia Adviser service is not yet known but it suggests that more needs to be done to highlight the availability and impact of this service and to raise awareness among GPs.

The CRS provides data on the number of referrals since service inception and the number, type and average length of time of contact interactions. These figures show the service building momentum in these early stages of development as well as the significant number of contact hours with clients. It also provides a unique look at the overall service and its engagement with service users. The preference for face-to-face meetings emphasises the importance of building a relationship with clients and understanding their needs which might be harder to achieve if you cannot see the person in the context of their home or community.

Results from the survey highlight the diverse needs of people with dementia and suggests early intervention placement of the Dementia Adviser service is in a good position to meet needs as they occur and change. Interestingly, in both the persons with dementia and carers, responses to the list of needs from most to least response do not change. While the majority of people identified 'Dementia', there were other areas that were identified by many respondents. Also interesting was the number who responded to the statement that they 'did not know if they needed any information'. Service users, who have been through the process of receiving a diagnosis of dementia, may still be unaware of the information they may need or the services that are available to them. The Dementia Adviser is in a unique position to provide tailored information based on that persons needs whether or not they are aware of them. This element of the role was identified in the Dementia Strategy as pivotal;

> *'Their actions would therefore be to identify what the problems might be, and then to signpost and facilitate engagement with the specialist services that can best provide the person with dementia and their carers with the help, care and support they need simply and quickly.'*

The findings also suggest clients did not know where to go to get the help they needed, and many were concerned, prior to meeting with the Dementia Adviser. This was clearly highlighted in both case studies as individuals reported being concerned prior to seeing the Dementia Adviser and did not know where to get help despite being referred from primary care facilities. Both case studies also show that peoples needs change over time and the Dementia Adviser was able to work with them as their needs changed. A recent study found that people with dementia who had a low-community involvement network had higher unmet needs (Miranda-Castillo *et al.* 2010a). The study found that those people with dementia who had attended a day hospital or a day centre over the previous three months had fewer unmet needs than those who had not although most participants did not use these services. The reasons for this are unknown but the authors suggest several possibilities for this including lack of knowledge about their existence. This highlights the potential of the unique placement of the Dementia Adviser in the care pathway and their ability to create a link between those living at home and the services available to them in the community.

When people with dementia did meet with their Dementia Adviser the majority felt listened to, respected and involved in the process. While many felt they were encouraged to make decisions, a small number of people with dementia disagreed with this statement. Dementia Advisers may rightly argue it is not their role to encourage service users to 'make decisions', rather to provide them with all the information they require in making a decision.

People with dementia and carers generally felt positive about the quality of the information provided. Most respondents felt the information was relevant, easy to understand and had been beneficial in helping them to access information and services both from the Alzheimer's Society and other organisations. Interestingly, a proportion of respondents reported that they needed more help to follow up on the information they were given. This demonstrates a need amongst people with dementia not only for information provided by Dementia Advisers but also for a more involved process of signposting to use the information. An appropriate person to assist in this area could be the Dementia Adviser Volunteer. The continued development and integration of Dementia Adviser Volunteers into the service is necessary to improve the pathway of information and signposting for service users and to make sure they get the most out of the service.

The most valued aspects of the Dementia Adviser service were also diverse. While the most valued part of the service was perhaps not surprisingly 'information about dementia and services', almost half of respondents chose 'the knowledge that someone is on my side'. Both of these outcomes are fundamental in the service specification and the responses are particularly pleasing given that the service focuses on the person with dementia rather than the carer. It is important that people with dementia feel that the Dementia Adviser is supporting them specifically rather than the carer. However, dependent on a client's specific need it may be necessary for a Dementia Adviser to refer a client to an Alzheimer's Society or external Advocacy service.

Also popular among respondents were the statements; 'the practical help received', 'emotional support' and 'trusted friendship'. While these areas of the service are not specifically highlighted in the expected outcomes of the service they are aspects of the service that people with dementia valued and felt were important. [6] This also highlights the multi-dimensionality of the service and its ability to provide a service tailored to individual need. It was also very pleasing to note that no respondent chose 'nothing, I don't value the service.' This indicates that all service users who responded to the questionnaire valued the service they had received. Free text responses certainly highlight the 'value' clients place on the service but for sometimes quite different reasons including; information, friendliness or understanding. This again emphasises the important role Dementia Advisers have in delivering information and support to clients which is based on the client's needs and wishes.

Responses from the questionnaire further indicate that clients 'value' the service as two-thirds of people with dementia felt they would be most likely to consult the Dementia Adviser in the future. This was more than the number who chose their 'carer' or 'family member' and significantly more than the number of respondents who felt they would contact a 'health or social care professional'. Carers' responses also indicate that people with dementia are more likely to consult their Dementia Adviser than their carers or family members. These findings show that the Dementia Adviser service has been of benefit to many of those living with

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[6] As a result of the findings of this report and the report from Stage 1 the Alzheimer's Society Dementia Adviser service specification is being revised as of February 2011.

dementia and that they feel confident to speak and receive information from their Dementia Advisers about any related enquiries.

The case studies included are useful in helping to understand the level and variation of service provision provided by a Dementia Adviser. The studies also clearly illustrate the 'journey' that many clients experience following dementia and the usefulness of the Dementia Adviser to help them negotiate this journey. The case studies also highlight the complexity of problems many clients face as a result of the dementia. While some problems, including anxieties about the condition, can occur immediately after diagnosis others may not necessarily manifest themselves until some months later highlighting the usefulness of the longevity of the Dementia Advisers contact. The case studies show the diverse range of individual client's needs, the breadth of knowledge required by a Dementia Adviser in able to support clients to live well with dementia, and finally the value these clients placed on their Dementia Adviser.

Strengths

The CRS data collection tool has been hugely beneficial to the development and reporting of the Dementia Adviser service. The CRS was a tool developed uniquely for the Dementia Adviser service and thus data capture has been centred on the needs of the Dementia Adviser, the service and their clients. The system is web-based which ensures there can be multiple users across multiple sites. The web-based system also ensures data cannot be lost easily and can be stored and accessed centrally. In this pilot, particularly comprehensive data has been captured regarding 'Contact Interactions'. The data clearly shows the frequency and duration of contact interactions providing the Society with a clear picture of the service model being delivered in the pathfinder sites. Furthermore, the detail recorded by the Dementia Advisers in the CRS regarding the individual, allows the reader a clear understanding of the diverse and complex needs of the service user as recorded in the Case studies A and B.

Overall 70 responses were received from people with dementia. Of these, 62 returned a questionnaire which is a 67% response rate from people with dementia. Almost a third of persons with dementia were able to complete the questionnaire on their own which is a positive finding for a service whose focus is on the person with dementia. It is also interesting to note there were few differences between the findings of the questionnaires for people with dementia and carers; including the proportion of missing responses.

The development of the questionnaire is robust in its method and as a result of the responses from this pilot the questionnaire has been further simplified as well as shortened before it was rolled out to all Alzheimer's Society Dementia Adviser sites. In particular the scale questions which regularly had 10% of responses missing were reduced from a 5 point scale to a 3 point scale. In the hope of further reducing the numbers of missing responses a number of questions were removed and the format changed to ensure it was clearer and easily readable. It is interesting to note that there were few differences between the findings of people with dementia and their carers; including the proportion of missing responses.

As a result of the successful development of this questionnaire, in particular involving service users in the development process of such tools, the Quality and Evaluation team have set up Local Service User Review Panels (2010/11). The panels are formed of people with dementia, who meet locally, in order to co-produce future service evaluation toolkits. The panels will also consult and pilot innovative non-verbal communication tools.

The findings of this study suggest the inclusion of the carer's questionnaire has been successful in improving validity. The proportion of responses from carers were higher than people living with dementia alone but were almost exactly the same as those from people with dementia who live with a carer. The carer's questionnaire has been especially useful in validating the 'missing' responses. As people with dementia had similar numbers of questions unanswered as carers, this suggests responses were missing either as a result of questionnaire design (including formatting, unclear instructions or lack of appropriate response items) or human error. This could have otherwise been attributed to the person's dementia.

Limitations

The collection of basic demographic data has proven challenging both from the CRS data and the questionnaire. Not enough data is recorded on the CRS to understand the population of clients by age or ethnicity and it is unknown if the Dementia Advisers are engaging a proportion of those considered vulnerable including the 'oldest-old' (those aged over 85), and those from Black or Minority Ethnic (BME) groups (Office for National Statistics and Department for Work and Pensions, 2005). Due to the level of missing ethnicity data currently collected on the CRS an ethnicity question was included in the questionnaire. This question was completed 'incorrectly' by a large proportion of respondents (75 %) who mostly answered 'British' or 'English' although some specified religions including 'Church of England' or 'Christian'. However the 17 option multi-choice question as defined in the UK 2001 census is too large for a survey this size. The format would also be inappropriately long considering the client group.

To ensure the Society is meeting the needs of vulnerable people, including BME communities, it is important we understand first if we are managing to deliver services to these groups. Due to missing data we do not have a clear idea yet who our client is. Therefore a more detailed examination of the needs of BME groups or the needs of younger clients for example, is not possible at this time. Understanding the client demographic is important to the future of the Dementia Adviser service and perhaps best captured using the CRS. It may be necessary to make changes to the CRS to ensure key demographic data for all clients is captured. The results of this report suggest making collection of some key demographic data on the CRS, including ethnicity, age, gender and living status, 'mandatory' responses which they are not currently. Further clarification of missing responses might include the options 'Do not know' and 'Not asked.' If demographic data collection on the CRS can be improved there is no need to include demographic detail in the questionnaire as details can be linked through the Client ID number.

Although the overall response rate for the questionnaire was high, more needs to be done to reach people with dementia who do not live with carers. The response rate for people with dementia living alone being significantly less than other client groups, suggests that their views of the service have not been wholly represented in this report. The evaluation method may need to be altered, for instance it might be necessary to offer a different environment for people with dementia living alone such as; one-on-one interviews, either in person or on the telephone.

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