

**The impact of an online support forum for carers of people with dementia**

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**Thesis declaration form**

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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## **Overview**

This thesis addresses computer-mediated interventions for carers of people with dementia and is comprised of three parts.

Part 1 is a literature review of computer-mediated interventions for carers of people with dementia. It systematically reviews research studies in this field published after January 2000.

Part 2, the empirical paper, is a mixed-methods evaluation of Talking Point, the UK Alzheimer's Society's online peer support forum for carers of people with dementia. Changes in new users' depression, anxiety and quality of the relationship with the person with dementia are examined over a 12 week period, and follow-up qualitative interviews are conducted with eight participants.

Part 3 is a critical appraisal of, and reflection on, the research and the manner in which it was conducted. It focuses on the following areas: issues in the evaluation of interventions for carers of people with dementia; the challenges of conducting research in a non-face-to-face context; the interview process; the extent of conclusions that can be drawn from the research and; future research.

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## **Part 1: Literature Review**

### **The effectiveness of computer-mediated interventions for informal carers of people with dementia**

## **Abstract**

**Aims:** Caring for a friend or relative with dementia is a burdensome and stressful experience. A range of psychosocial interventions have been developed to support such carers, and more recently some of these interventions have been delivered by computer. This systematic review aims to evaluate the effectiveness of computer-mediated interventions for carers of people with dementia.

**Methods:** Databases and reference lists were searched for papers published between January 2000 and September 2012 that evaluated the effectiveness of computer-mediated interventions for carers of people with dementia. Thirteen empirical studies were identified and evaluated.

**Results:** Empirical studies described and evaluated a wide range of complex and multi-faceted interventions. This made direct comparison of studies difficult.

Overall, evidence for such interventions is mixed but generally positive.

**Conclusions:** This review found evidence to support the effectiveness of computer-mediated interventions for carers of people with dementia. Future research studies could benefit from being of higher quality, for example with more clearly defined aims, having a control groups and having adequate levels of power, and multi-method in their approach in order to tap into a greater range of factors of importance to carers.

## **Introduction**

The wellbeing of informal carers of people with dementia is an important public health issue. There are currently about 750 000 people in the UK with dementia (Alzheimer's Society, 2011). Some live in residential care, but many are cared for at home by a relative or friend. Caring for an elderly relative with disability is burdensome and stressful, and negatively affects the carer's social, family and professional life (Schulz, O'Brien, Bookwala & Fleissner, 1995). Carers of people with dementia frequently report feelings of isolation and inadequate social support (Stoltz, Udén & Willman, 2004). The risk of anxiety and depressive disorders is increased (Schulz & Martire, 2004). The combination of loss, the physical demands of caregiving, prolonged distress, and biological vulnerabilities of older carers may also compromise their physical health (Schulz & Martire, 2004) and mortality (Schulz & Beach, 1999). Thus, their ability to function as carers can be compromised. The carer-patient relationship can affect the progress of the dementia, with evidence that high levels of expressed emotion are predictive of increased negative behaviours in the person with dementia over time (Vitaliano, Young, Russo, Romano & Magana-Amato, 1993).

### **Support for carers of people with dementia**

There exists a range of support interventions for carers of people with dementia to counteract these problems. Interventions can broadly be divided into two categories: those aimed at providing information and improving the carer's wellbeing and coping skills (for example, psychoeducational interventions and support groups); and those aimed at reducing the objective amount of care provided by carers (for example, interventions that improve the patient's competence in daily activities) (Michon, Weber, Rudhard-Thomazic & Giannakopoulos, 2005). While not all

interventions can be neatly delineated, this review is primarily concerned with the former category.

Beauchamp, Irvine, Seeley and Johnson (2005) note that the most effective interventions have multiple components, addressing two or more of the following: knowledge (generally about dementia, and also available community resources); affect (for example, management of the carer's emotions); cognitive skills (for example, problem solving); and behavioural skills (for example, ability to access social support). Pusey and Richards (2001) conducted a systematic review of 30 controlled studies of psychosocial interventions for carers of people with dementia. Psychosocial interventions were defined as "interpersonal interventions concerned with the provision of information, education, or emotional support together with individual psychological interventions addressing a specific health and social care outcome" (Pusey & Richards, 2001, p.108). While they found the overall methodological quality of the studies to be poor, they found that individualised interventions that utilised problem solving and behaviour management demonstrated the best evidence of effectiveness. Thompson et al.'s (2007) systematic review of information and support interventions for carers of people with dementia found little evidence that interventions aimed at supporting and/or providing information to carers of people with dementia were uniformly effective. Their systematic review found evidence that group-based supportive interventions impacted positively on psychological morbidity, though cautioned that the clinical significance of this finding should be interpreted tentatively. They found no evidence for the effectiveness of any other form of intervention on a range of physical and psychological health outcomes.

## **Non-traditional support for carers of people with dementia**

The commitments of caring and other logistical issues, such as living in a remote rural area, can make accessing interventions or other services problematic. Colantonio, Cohen and Pon (2001) note that there is evidence suggesting that uptake of traditional face-to-face dementia services, both for patients and carers, has been low. While some modestly effective psychosocial interventions have been designed for carers of people with dementia, these interventions can be hard to access (Bank, Argüelles, Rubert, Eisdorfer & Czaja, 2006). Time constraints, lack of respite care, transport issues and health issues have been identified as reasons why carers often do not engage in the face-to-face support services that are available (Galinsky, Schopler & Abell, 1997).

Colantonio et al. (2001) found that carers of people with dementia showed “great interest” in support services other than traditional face-to-face support groups, for example, telephone support, newsletters and computer services. Increasingly, non-traditional (non-face-to-face) forms of support for carers of people with dementia are being developed, and there is a growing body of research into such interventions. Some of these non-traditional interventions are similar to more traditional interventions, and only vary in the medium through which they are delivered. For example, cognitive behaviour therapy (CBT), which is traditionally delivered in a face-to-face context, can also be delivered over the telephone (see, for example, Glueckauf et al., 2007; Wilz & Schinköthe, 2011) and educational sessions that were traditionally delivered face-to-face can also be delivered on video or DVD (see, for example, Gant, Steffen & Lauderdale, 2007). In other instances, however, non-traditional mediums open up a range of new possibilities for the way in which, and the extent to which, carers can be supported. For example, one way in which

internet support groups can go beyond more traditional face-to-face groups is that people are able to support one another twenty four hours a day, seven days a week. Individuals who are physically distanced from one another can communicate through internet support groups. This is particularly helpful for individuals who are physically isolated or experiencing uncommon problems (White & Dorman, 2001).

### **Evaluating carer support interventions**

Evaluation of carer support interventions is problematic. Standardised assessment of interventions remains challenging due to the diversity of aims and outcomes measured. Gallagher-Thompson and Coon (2007) note that numerous reviews have “failed to identify any one consistently effective method for reducing distress or improving psychological well-being in family caregivers of cognitively impaired older adults”. Michon et al. (2005) argue that research in carer intervention outcomes is frequently lacking in focus, with a lack of designed interventions and theoretically driven outcome measures. They note that sample sizes are too small to reach statistical significance, control groups are often lacking, descriptions of proposed interventions are vague, and instruments are not sensitive enough to identify significant changes after treatment. This can make the development of effective support for carers of people with dementia challenging.

### **Previous reviews**

Powell, Chiu and Eysenbach (2008) conducted a systematic review of networked technologies supporting informal carers of people with dementia. They identified 15 papers published up to August 2007 that described five different interventions. They found that the interventions were multifaceted, with inconsistent outcomes, but suggested that the interventions had moderate effects on improving carer stress and depression. It was found that treatment effects varied with carer

characteristics such as ethnic group, formal support and baseline burden. This review was published as a brief descriptive report, and its evaluation of studies is therefore limited. In addition, with the rapid development of the internet and other computer technologies, it is somewhat outdated.

A recent French review (Wu, Faucounau, de Rotrou, Riguet & Rugaud, 2009) looked at studies of information and communication technology interventions supporting carers of people with dementia. Sixteen papers concerning nine intervention programmes (internet and telephone interventions) were described, without a critical analysis or comparison of studies, and with limited conclusions drawn.

### **Aims of this review**

Computer-mediated interventions for carers of people with dementia is a growing area and a wide range of different interventions have been developed in recent years. In order for future interventions to be as effective as possible, and to ensure that service providers are aware of the relative strengths and weaknesses of different interventions, it is important for research into this area to be critically evaluated. This review therefore asks the question: how effective are computer-mediated interventions for informal carers of people with dementia?

### **Method**

#### **Criteria for the inclusion and exclusion of studies**

Studies had to meet several criteria in order to be eligible for inclusion.

1. The study must relate to computer-mediated interventions. This could include DVDs, CD-ROMs, the internet, or computer programs, but excludes studies that exclusively consider the telephone. The intervention does not need to exclusively be computer-mediated, but this must be the main part of the intervention.

2. Interventions must include therapy, professional or peer support programmes, educational or information programmes. They must not primarily be technologies such as surveillance or GPS to assist carers in their role.

3. Carers in studies must be informal, that is, they must not be paid carers such as nursing home staff.

4. Studies must include dementia as the diagnosis of the person being cared for, but do not have to be limited to it.

5. Studies must use at least one quantitative measure to assess the outcome of the intervention on carer wellbeing, ability to cope, or knowledge. These measures do not need to be standardised, and can be questionnaires asking for users' views of the effects of the intervention. Studies using only questionnaires that consider features of the intervention, such as its convenience, user-friendliness or accessibility, would be excluded.

6. Studies can be randomised-controlled trials, pre and post-test studies with or without a control group, or post-test only studies with or without a control group.

7. Studies must be peer reviewed journal articles, written in English, published between January 2000 and September 2012.

### **Literature search strategies**

PsychINFO, MEDLINE and CINAHL Plus were searched for articles from January 2000 to September 2012. The lower limit was placed because this review is focused on current technologies.

The literature search used keywords and thesaurus searches. Keyword searches were organised into four concept areas and were conducted as follows:

computer\* OR DVD\* OR internet\* OR network\* OR technolog\* OR ICT OR  
online\* OR CD-ROM\*  
AND  
intervention\* OR train\* OR therap\* OR support\* OR treatment\*  
AND  
carer\* OR caring \* OR caregiv\* OR family\* OR families\* OR parent\* OR mother\*  
OR father\*  
AND  
dement\* OR Alzheimer\*

The searches of PsychINFO, MEDLINE and CINAHL Plus databases generated 262, 708 and 248 papers respectively. After de-duplication, there were 948 papers.

All titles and abstracts of the 948 papers were examined to see whether they met inclusion criteria. Thirty-one papers could not be excluded on the basis of title and abstract alone. These 31 papers were read in full.

Eighteen of these 31 papers were excluded. Seven studies were excluded because it was not apparent from the title or abstract whether the intervention was computer-mediated, but further investigation revealed that it was not. Five were excluded because the evaluation of the intervention was limited to anecdotal reports, qualitative interviews, and/or usage or intervention acceptability information. One paper was a literature review, one study was a description of an intervention, one was a research proposal, one was a study into how important people perceived elements such as social support to be, one was a meta-analysis, and one investigated whether older carers were able to complete standardised questionnaires. Where there was a

query about a paper's eligibility for inclusion, two other experienced researchers were consulted in order to reach consensus according to inclusion criteria.

This left a total of 13 papers for inclusion in the review. See Figure 1 for a flow diagram of inclusion and exclusion of papers in this review. In two instances, two papers reported results from the same research study (Chiu et al., 2009; Chiu & Eysenbach, 2010; also Glueckauf, Ketterson, Loomis & Dages, 2004; Glueckauf & Loomis, 2003). For the purpose of clarity, when these studies are referred to, Chiu et al. (2009) and Glueckauf and Loomis (2003) will be referenced.

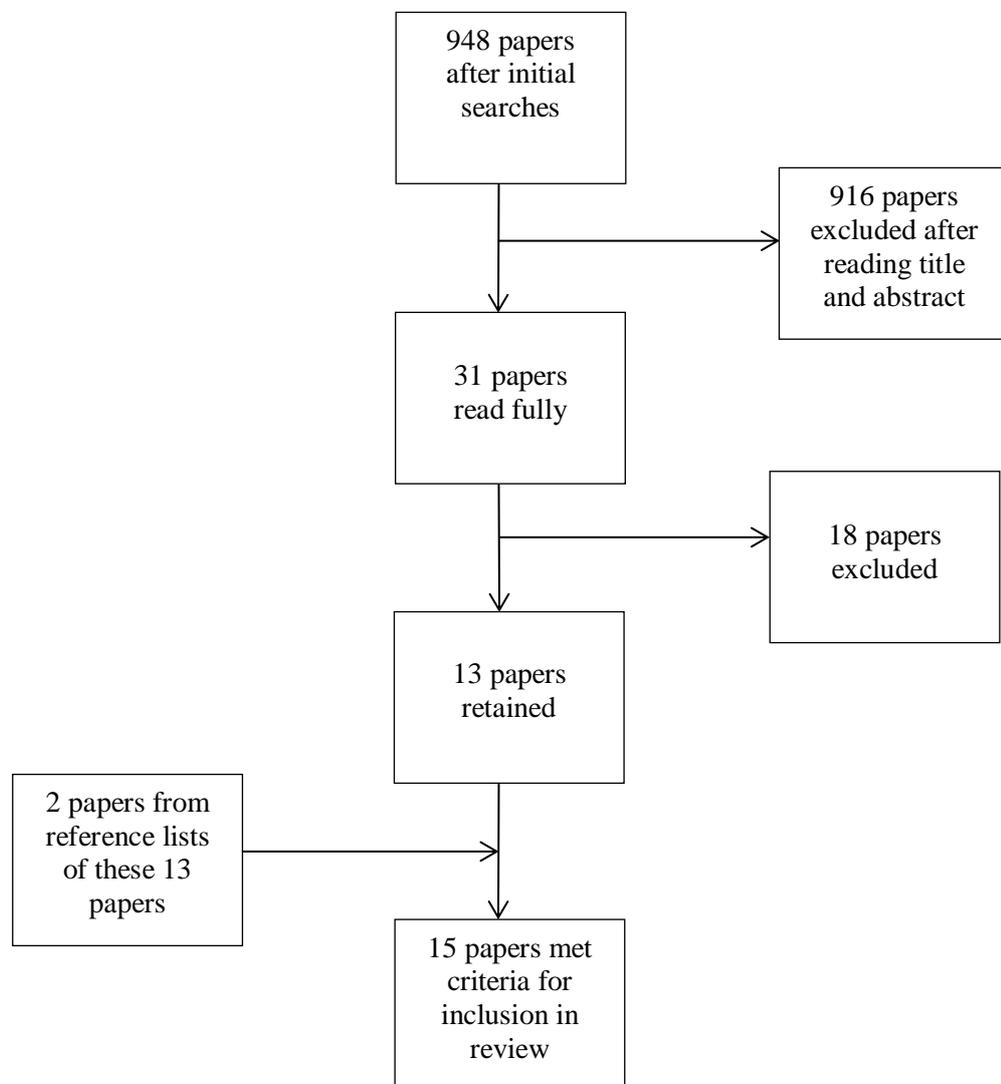


Figure 1: Flow diagram of studies included and excluded

## **Searching other resources**

Reference lists of the papers included in this review, as well as reference lists from Powell et al. (2008) and Wu et al. (2009), were examined to see whether any additional papers were eligible for inclusion. This led to four further papers being examined, yielding two additional papers (Magnusson, Hanson & Nolan, 2005; Marziali & Donahue, 2006). The reference lists of these papers were also searched, leading to one further paper being examined, but no further eligible studies were identified.

## **Quality assessment**

The quality of each study was evaluated using Downs and Black's (1998) checklist for the assessment of the methodological quality of both randomised and non-randomised studies of healthcare interventions (see Appendix 1). In light of the nature of the studies being evaluated, several items on the checklist were not relevant (items 8, 13, 14 and 19), and were therefore excluded from the assessment. For example, item 14 asked whether any attempt was made to blind study subjects to the interventions that they received, which is not relevant for most psychological intervention studies. Item 27, which relates to the power of studies, was modified so that a study scored 1 if a power calculation was specifically referred to and the study had adequate power to detect a statistically significant effect, and scored 0 if the study was underpowered, or a power calculation was not reported. Table 1 summarises the items from Downs and Black's (1998) checklist. Please see Appendix 1 for more details of scoring criteria and excluded items.

Table 1: Items from Downs and Black's (1998) quality assessment checklist that were used in this review

## **Results**

A total of 15 papers met criteria for inclusion. Because of study repetition across two pairs of papers, this means that 13 empirical studies are evaluated. Many papers describe mixed methodology studies, for example, a qualitative evaluation of a programme as well as a quantitative evaluation. This review is only concerned with

those sections of research studies that meet inclusion criteria, and does not comment on, for example, qualitative components of studies. Table 2 provides a summary of the 13 studies.

Table 2: Study Characteristics

Author and date	Participants	Initial sample size*	Intervention	Aims of study	Measures	Design	Principal findings
Beauchamp et al. (2005)	Employed family carers in USA	325	Worksite-based internet multimedia programme: "Caregiver's Friend: Dealing with Dementia". Programme provided text materials and videos that modelled positive caregiving strategies. 30 days exposure. (Control: wait list)	Can exposure to the programme: a) improve carer appraisals?; b) increase the use of constructive coping skills?; c) reduce the negative outcomes of depression, anxiety and strain?; d) increase positive perceptions of caregiving?	Items used from: CES-D; STAI; CSI; PAC	Pretest-posttest RCT; Follow up at end of intervention	Treatment group reported greater gains with respect to measures of self-efficacy, intention to get support and caregiver gain, and reductions in carer stress, strain, depressive symptomatology, and state anxiety <sup>^</sup> .
Chiu et al. (2009)	Chinese Canadian family carers of elderly patients with Alzheimer's disease and related dementias	35	Internet-based Caregiver Support Service (ICSS): An online carer information handbook, and exchange of e-mails between caregivers and Chinese professional clinicians (occupational therapists). 6 months access.	To explore usage behaviour associated with outcomes and to evaluate effects of participation in ICSS on carer health outcomes	BSFC	Single group pretest-posttest. Follow up at end of intervention.	Non-users had an increase in perceived burden post-intervention, while frequent users had a decrease of burden score <sup>^</sup> .
Eisdorfer et al. (2003)	Cuban American and White American family carers of people with Alzheimer's Disease and related dementias	225	Part of the REACH (Resources for Enhancing Alzheimer's Caregiver Health) programme. 3 conditions: a) structural ecosystems therapy b) structural ecosystems therapy + computer-telephone integration system c) minimal support condition 12 month interventions.	To examine the efficacy of the two interventions across Cuban American and White American carers and to examine the efficacy of the interventions over time. To explore the differential effects of the treatment across varying carer-care recipient dyads.	CES-D	Pretest-posttest RCT; measures at baseline, 6, 12 and 18 months.	Carers in condition (b) experienced reduction in depressive symptoms at 6 months relative to other conditions <sup>^</sup> . 18 month follow up indicated the intervention was particularly beneficial for Cuban American husband and daughter carers <sup>^</sup> .

Finkel et al. (2007)	Family carers of dementia patients	46	Provision of information about dementia and community resources and strategies to enhance safety, communication, self-care, social support, and management of problem behaviours – delivered through the customised Computer-Telephone Integration System. 6 month intervention. (Control: information only)	Evaluate intervention effectiveness	CES-D; 3 questions assessing the primary domains of the RMBPC; modified version of CHHBS; a Received Social Support Scale from the ISSB	Pretest-posttest RCT; 6 months follow up	Carers in intervention condition reported a decrease in burden post intervention <sup>^</sup> , and those who evidenced high depression at baseline experienced a decline in depression <sup>^</sup> .
Gallagher-Thompson et al. (2010)	Chinese American carers living in the San Francisco Bay area	70	CBT skill training programme delivered on a DVD (plus workbook). 12-16 week intervention. (Control: general educational DVD programme on dementia, plus written materials to supplement)	Hypothesis – that the skill training DVD treatment would be more effective than the educational DVD in reducing conditional bother, increasing positive affect, and reducing other negative symptoms of depression.	CES-D; RMBPC; Programme evaluation questionnaire	Pretest-posttest RCT; follow up 16 weeks after baseline.	The two interventions did not differentially affect level of depressive symptoms; positive affect subscale score of CES-D increased more for those in skill DVD group <sup>^</sup> . Reaction to problems decreased in skill DVD group <sup>^</sup> . Both groups reported the intervention improved their confidence and skills in caring, with the skill DVD group generally reporting greater gains.
Glueckauf and Loomis (2003)	Carers of individuals with progressive dementia from Maryland, Florida (bar one)	40	Alzheimer's Caregiver Support Online (AlzOnline) – an internet- and telephone-based education and support network for carer of individuals with progressive dementia. 16 week intervention on average.	Initial program evaluation of AlzOnline's Positive Caregiving Classes. Objectives: To assess the impact of the programme on the psychosocial functioning of carer participants, particularly their perceptions of self-efficacy, emotional growth, and burden from the caregiving experience.	CSES; SRGS; CAI	Single group pretest-posttest	Participants reported pre- to post-class increases on all 3 CSES subscales, and concomitant decreases in subjective carer burden <sup>^</sup> . There were substantial improvements in their perceptions of self-efficacy in performing routine caregiving duties and managing challenging care recipient behaviours, and their appraisals of the emotional caregiver burden from pre- to post-testing phase <sup>^</sup> .

Lewis et al. (2010)	Carers of people with dementia in USA	63	Internet-Based Savvy Caregiver (ISBC) – an internet-based psychoeducational programme	To establish feasibility and acceptability of programme	Follow-up questionnaire	Single group posttest	Participants found the programme educational, convenient, useful, and interesting. They endorsed feeling more confident in caring skills and communication with their family.
Mahoney et al. (2003)	Family carers of people with Alzheimer's Disease in USA	100	Part of the REACH (Resources for Enhancing Alzheimer's Caregiver Health) programme. Technology intervention –access to a computer-mediated automated interactive voice response (IVR) intervention. 12 month intervention. (Control: usual care)	To investigate whether this system could reduce stress associated with caring for a family member with Alzheimer's related disruptive behaviours.	RMBPC; SAI; CES-D	Pretest-posttest RCT; measures at baseline, 6, 12 and 18 months.	Participants with lower mastery at baseline showed improvement in bother, anxiety and depression <sup>^</sup> . Wives showed a reduction of the bothersome nature of caregiving <sup>^</sup> .
Magnusson et al. (2005)	Family carers of older people in two municipalities in the west of Sweden. Carers: 16 stroke, 5 dementia, 5 diabetes and various other	34	Swedish ACTION (Assisting family Carers using Telematics Interventions to meet Older persons' Needs) project: An ICT service providing carers with information, education and support. Intervention ranged from 3 months to 1 year.	Programme evaluation	Modified version of the PREP evaluation questionnaire	Single group posttest	The intervention had a moderately positive effect on the preparedness, rewards and satisfaction of caring.
Marziali and Donahue (2006)	Family carers in Canada of older adults with neurodegenerative diseases (Alzheimer's; stroke-related dementia; Parkinson's)	66	"Caring For Others" intervention programme. Intervention group received computers and access to a website with links to information, e-mail and threaded discussion, video-conferencing link (→ 10-session manual-guided psychosocial support group facilitated by a group therapist, followed by 12 additional online sessions facilitated by a group member).	To evaluate the effects of the intervention on carers	HSQ-12; CES-D; a measure requiring carers to endorse presence/absence of activities of daily living and instrumental ADLs performed for care recipient, rating degree of	Pretest-posttest RCT; measures at baseline and 6 month follow up	Intervention group experienced a decline in stress <sup>^</sup> .

			22 week intervention. (Control: no intervention)		stress for each; RMBPC; MSPSS		
Marziali and Garcia (2011)	Canadian carers (French and English speaking) from 3 cities	91	Two internet interventions: a text-based chat group (including access to a carer information handbook and 6 videos on managing caregiving tasks); and video conferencing psychotherapeutic support group intervention facilitated by a clinician, plus access to a carer information handbook. 6 month intervention for chat group; 20 week intervention for support group.	To examine the impact on dementia carers' experienced stress and health status	HSQ-12; CES-D; SMAF	Two group pretest-posttest, with follow up at 6 months	In contrast to the chat group, the video group showed greater improvement in mental health status^.
Rosen et al. (2003)	Family members ("primary decision makers") of nursing home residents with dementia living in nursing homes around Pittsburgh, Pennsylvania, USA.	18	Computer-based education on dementia, agitation/aggression, and carer stress. 45 minute intervention.	To enhance family participation in nursing home care	Knowledge questionnaire	Single group pretest-posttest	Knowledge of the key principles of dementia care improved^.
Torp et al. (2008)	Elderly ( $\geq 60$ years old) spousal carers of people with diagnosis of dementia or stroke, in Norway, who were computer novices. Carers: 14 cerebral	19	Training for carers on how to use and collect information from the Internet. All computers were connected in an online discussion forum. Also videophone contact between participants. Call centre run by professionals who provided support on use of ICT, and	To explore whether use of ICT by informal carers of frail elderly people living at home would enable them to gain more knowledge about chronic illness, caring and coping, establish an informal support network, and	FFCS; a measure of social support; RSS; GHQ-20; questions about ICT use and knowledge about chronic disease	Single group pretest-posttest with measures at baseline and 12 months	Carers reported extensive use of the ICT service. After the intervention, they had more social contacts and increased support and less need for information about chronic illness and caring^.

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stroke, 5 dementia	advice and support regarding participants' caring situation. 12 month intervention.	reduce stress and related mental health problems.	and caring
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^Statistically significant at  $p < 0.05$

\*i.e. sample size at the start of the study, before any participants dropped out

CES-D=Center for Epidemiologic Studies-Depression scale; STAI=State-Trait Anxiety Inventory; CSI=Caregiver Strain Instrument; PAC=Positive Aspects of Caregiving; BSFC=Burden Scale for Family Caregivers; RMBPC=Revised Memory and Behaviour Problems Checklist; CHHBS=Caregiver Health and Health Behaviours Scale; ISSB=Inventory of Socially Supportive Behaviours; CSES=Caregiving Self-Efficacy Scale; SRGS=Stress-related Growth Scale; CAI=Caregiver Appraisal Inventory; SAI=State Anxiety Inventory; HSQ-12=Health Status Questionnaire 12; MSPSS=Multidimensional Scale of Perceived Social Support; SMAF=Functional Autonomy Measurement System; FFCS=Family and Friendship Contacts Scale; RSS=Relative Stress Scale; GHQ-20=General Health Questionnaire 20

## **Interventions**

Many interventions for carers of people with dementia include a range of components, and indeed it is suggested that such interventions are more effective than single component interventions (Beauchamp et al., 2005; Sørensen, Pinquart & Duberstein, 2002). The studies considered in this review reflect this trend, and many described multi-component interventions.

The aims of interventions tended to be to reduce carer distress, and increase carers' competence in caregiving. One study had the aim of enhancing family participation in nursing home care (Rosen et al., 2008). Four studies were described as pilot studies or feasibility studies (Marziali & Donahue, 2006; Marziali & Garcia, 2006; Rosen et al., 2003; Torp et al., 2008). Some studies were not described as pilot studies but nonetheless involved the development and evaluation of a new computer-mediated intervention for informal carers of people with dementia (for example, Chiu et al., 2009; Glueckauf & Loomis, 2003), highlighting the fact that computer-mediated interventions are a growing area in dementia carer support.

The 13 studies investigated a range of interventions. While each intervention had at least some computer-mediated delivery, many also included other components. Research suggests that in order for carer interventions to be effective they may need to be multicomponent in their nature (Beauchamp et al., 2005), but this does mean that careful study design is required in order to separate out which components of an intervention are effective, or how they work in combination to offer an effective intervention to carers.

Six papers described interventions that included the ongoing involvement of a professional. One paper described a study comparing two interventions: one which included professional involvement and another which did not. Five papers described

interventions that, once set up, did not require the ongoing involvement of a professional. Magnusson et al. (2005) described ACTION, a Swedish intervention which was an ICT-based service providing carers with information, education and support in their caring role, though it is not clear whether professionals had a role in the ongoing delivery of the intervention, as it is not well described.

In only one study did it seem that the intervention was continued after it was evaluated (Torp et al., 2008). This is somewhat surprising, given that one of the benefits of computer-mediated interventions, particularly those that make use of the internet, is that they can be used on an ongoing basis. Individual interventions varied in terms of the intensity of input over the time period that they were offered. Sometimes this was purely due to the amount that participants chose to make use of the intervention or service, and in other instances it was because of the designed intensity of the intervention, such as weekly online support groups (Marziali & Garcia, 2011).

### **Quality assessment**

The quality of each study was evaluated using Downs and Black's (1998) checklist for the assessment of the methodological quality of both randomised and non-randomised studies of healthcare interventions. Table 3 shows the results of this quality assessment, showing domain scores and total scores for each study. Each study could achieve a score between 0 and 24, with higher scores indicating better quality studies. Studies ranged in quality, achieving scores between 5 (Magnusson et al., 2005) and 21 (Mahoney et al., 2003).

Table 3: Quality assessment of studies

Author and date	Reporting Max = 10	External validity Max = 2	Internal validity – bias Max = 5	Internal validity – confounding (selection bias) Max = 6	Statistical power Max = 1	Overall quality Max = 24
Beauchamp et al. (2005)	10	1	4	5	0	20
Chiu et al. (2009)	7	0	3	2	0	12
Eisdorfer et al. (2003)	9	1	4	4	0	18
Finkel et al. (2007)	8	0	2	3	0	13
Gallagher-Thompson et al. (2010)	10	1	3	4	0	18
Glueckauf and Loomis (2003)	7	0	3	0	0	10
Lewis et al. (2010)	7	0	2	0	0	9
Mahoney et al. (2003)	10	1	5	5	0	21
Magunsson et al. (2005)	3	0	2	0	0	5
Marziali and Donahue (2006)	7	0	2	3	0	12
Marziali and Garcia (2011)	8	0	3	3	0	14
Rosen et al. (2003)	6	0	1	1	0	8
Torp et al. (2008)	7	0	4	0	0	11

## Design

Initial sample sizes ranged from 18 (Rosen et al., 2003) to 325 (Beauchamp et al., 2005), with a range of dropout rates. Dropout rates are an important issue as high dropout rates undermine study validity, and also raise questions about the acceptability of interventions to participants. Although a number of papers reported

whether or not the characteristics (such as age and baseline depression score) of those who dropped out of the research were different to those who did not, only one study conducted an intention to treat analysis of results (Chiu et al., 2009) and one interpolated 18 month follow up scores where data was available (Eisdorfer et al., 2003).

No study provided a power calculation, and several authors noted that their study was likely to be underpowered. This is unfortunate, as it raises questions about whether non-significant results were in fact due to a Type II error. Several studies with small sample sizes used qualitative interview data alongside quantitative data in order to add information about participants' experiences of the intervention (for example, Magnusson et al., 2005; Torp et al., 2008), although this material is not evaluated in this review.

A common weakness in studies was that follow-up periods were short; typically follow-up took place at the termination of the intervention. Reporting of follow-up periods was often not present or was ambiguous, and only Mahoney et al. (2003) and Eisdorfer et al. (2003) described follow-up periods that extended beyond the end of the intervention. Short follow-up periods mean that the longer term effects of the interventions on carers cannot be evaluated.

### **Measures and outcomes**

Most studies used a large number of outcome measures. This is advantageous because interventions for carers of people with dementia often target a range of areas such as carer mood, caring skills and carer burden, and it is important to understand the effects of an intervention on all the areas that they aim to target. However, in several studies, the use of a large number of measures led to selective reporting of results and data dredging (for example, Finkel et al., 2007; Marziali & Donahue,

2006), and it was not always made explicit why certain measures were selected as outcome measures. The range of measures used in studies raises questions about what constitutes “effectiveness”, since there are so many possible domains that can be evaluated.

Studies used a wide range of carer self-report measures to evaluate interventions, and most studies used more than one outcome measure. The review of findings of studies is grouped according to outcomes measured.

### *Mood and mental health*

Eight studies used measures of mental health, which included measures of depression, anxiety, and also measures looking at carer mental health more broadly.

#### *Depression*

Seven studies included measures of depression, and a range of effects of interventions in relation to depression was reported. All of these studies used variants of the Center for Epidemiologic Studies Depression Scale (CES-D). The CES-D has good psychometric properties, and evidence suggests that its psychometric characteristics are the same for individuals who are physically unwell, making it an appropriate measure across the health-illness groups (Devins et al., 1988). This is a pertinent consideration for carers of people with dementia whose physical health is often compromised (Schulz & Martire, 2004).

Two studies found an improvement in CES-D scores (Beauchamp et al. 2005; Eisdorfer et al., 2003), and both of these studies were of higher quality (scoring 20 and 18 respectively). In two studies, with quality scores of 21 and 18, hypotheses were partially supported in relation to CES-D scores (Gallagher-Thompson et al., 2010; Mahoney et al., 2003), with studies showing some favourable effects of the intervention on carer depression. One study, with a quality score of 13, did not find a

main effect of depression, but conducted a number of post-hoc tests and did find an effect (Finkel et al., 2007). One study, with a quality score of 12, did not find any effects (Marziali & Donahue, 2006), and one, with a quality score of 14, did not report the results of the CES-D, despite using it as an outcome measure (Marziali & Garcia, 2011).

Beauchamp et al. (2005) conducted a dose-response analysis, which revealed that more time spent viewing the internet program was associated with greater change in outcome. Eisdorfer et al. (2003) found that the efficacy of the intervention differed according to ethnicity and type of carer, in terms of their relationship to the person being cared for. In this study, randomisation into treatment condition was stratified according to participant ethnicity, but was not stratified according to carer-care recipient relationship, so it is possible that the main effects reported are at least in part explained by the moderating effect of carer-care recipient relationship. Eisdorfer et al.'s (2003) study is unusual in that follow up took place at multiple time points, up to 18 months, which is a strength of the research.

Although Mahoney et al. (2003) did not provide a power calculation, they noted in their discussion that their sample size was "less than desired" for their carer outcome analysis, and hypothesised that this may mean that the lack of a main effect for the intervention may be due to a Type II error.

Finkel et al.'s (2007) post-hoc tests found that as baseline depression increased, carers in the intervention group demonstrated greater improvements in depression. Marziali and Garcia (2011) used a range of outcome measures, including the CES-D, but then selectively reported results, and did not report any results in relation to this measure. The authors did not comment on depression until the discussion section, in which they noted that carers were not clinically depressed (as

measured by the CES-D) at baseline or follow up, but did not provide any descriptive statistics.

In summary, seven studies investigated carer depression, with five finding some favourable effect of the intervention on carer depression, though for one study this result was only found after conducting post-hoc tests. Those studies in which positive effects were found were of higher quality than those studies that did not find any effects. A number of the studies had small sample sizes, and power and sample size is an issue pertinent to all of the studies in this review.

#### *Anxiety*

Only two studies used measures of anxiety (Beauchamp et al., 2005; Mahoney et al., 2003). Both studies were of higher quality, with scores of 20 and 21, and both measured state anxiety from the State-Trait Anxiety Inventory (STAI). It was pertinent to remove the trait section of the measure, as any carer intervention would not be expected to affect participants' trait anxiety.

Overall, evidence from these two studies suggests that the computer-mediated interventions had favourable effects on carer anxiety. One study (Mahoney et al., 2003) only found this favourable result in relation to participants with mid-low levels of mastery at baseline.

#### *General mental health*

Three studies (Beauchamp et al., 2005; Marziali & Garcia, 2011; Torp et al., 2008) considered mental health in a broader sense than anxiety or depression. One was of higher quality (Beauchamp et al., 2005, quality score 20) and the other two were of somewhat lower quality (Marziali & Garcia, 2011, quality score 14; Torp et al., 2008, quality score 11). Beauchamp et al. (2005) used two subscales from the Revised Ways of Coping, but did not find any differences over time between the

control group and the treatment group. Torp et al. (2008) did not find favourable results, and Marziali and Garcia (2011) found results after conducting post-hoc tests. Marziali and Garcia (2011) used the Health Status Questionnaire 12 (HSQ-12) as an outcome measure. Although when the authors described the outcome measures for their study, they referred to this measure as an overall measure of carer health, in their results they selectively commented on the mental health subscale of the measure. They found that compared with an online chat group intervention, participants in an online videoconferencing support intervention showed greater improvement on the mental health subscale of the HSQ-12 over time. The authors did not report any other effects in relation to the HSQ-12 or any of its subscales. Given that measures were broken down into their subscales, it is likely that a number of statistical tests were performed in order to generate these results, although the authors did not report any corrections made to control the familywise error rate.

#### *Carer physical health and health behaviours*

Marziali and Donahue (2006) measured carer physical health and Finkel et al. (2007) measured carer self-care activities. Neither study reported any favourable effects. Both of these studies were of relatively lower quality, with scores of 12 and 13 respectively.

#### *Carer stress and burden*

Eight studies used measures of carer stress or burden. Four used variants of the Revised Memory and Behaviour Problems Checklist (RMBPC) (Finkel et al., 2007; Gallagher-Thompson et al., 2010; Mahoney et al., 2003; Marziali & Donahue, 2006). This measure is a reliable and valid tool for the assessment of both the presence of behaviour problems in dementia patients, as well as the extent of carer burden associated with these problems (American Psychological Association, 2012).

One study (Glueckauf & Loomis, 2003) separated the Caregiver Appraisal Inventory into its subscales and analysed perceived positive dimensions of caring and burden of caring separately. Positive dimensions of caring is considered below (“Measures of positive aspects of caring”).

Four studies, with quality scores of 20, 18, 10 and 14, found positive effects of the intervention on carer burden (Beauchamp et al., 2005; Gallagher-Thompson et al., 2010; Glueckauf & Loomis, 2003; Marziali & Garcia, 2011). In three studies the research found some effects of the intervention on carer burden (Chiu et al., 2009; Mahoney et al., 2003; Marziali & Donahue, 2006). These studies received quality scores of 12, 21 and 12 respectively. One study, with a quality score of 11, found no effect on carer burden as a result of the intervention (Torp et al., 2008).

Gallagher-Thompson et al. (2010) found that mean “upset or bother” reaction to total number of problems (memory problems, depressive symptoms of person with dementia, and disruptive behaviours) as measured by the RMBPC, differed between the two intervention groups, with the mean reaction for the skill DVD group decreasing, but remaining essentially the same for the education DVD group. This highlights that information alone may not be enough to reduce carer “bother” in relation to care recipient behaviours. It is possible, however, that information, in combination with other forms of support, may be effective.

Chiu et al. (2009) found that the pre-post change score on the Burden Scale for Family Caregivers (BSFC) was not significant. However, they then grouped study completers into non-users (n=9), occasional users (n=8) and frequent users (n=11). Differences in BSFC change scores were not significant between the three groups, but were significant between non-users and frequent users. Chiu et al. (2009) also used seven other measures in addition to their primary outcome measure

(BSFC), but only reported descriptive statistics for participants at baseline in relation to these measures.

Marziali and Donahue (2006) did not find a difference between intervention and control groups at follow up in relation to scores on either the RMBPC or their other measure in relation to stress associated with activities of daily living. They conducted a post-hoc test using the combined scores from these two measures to look at “experienced stress”. It was found that there was an effect for the intervention condition in reducing stress, and this was not the case for the control condition.

#### *Carer social support*

Three studies used measures of social support (Finkel et al., 2007; Marziali & Donahue, 2006; Torp et al., 2008) with varied findings. None of these studies received scores indicating that they were of particularly high quality; they scored 13, 12 and 11 respectively. Carer social support is a pertinent area to consider, as carers of people with dementia frequently report feelings of isolation and inadequate social support (Stoltz et al., 2004).

Finkel et al. (2007) found that although there were no main effects for received social support, those in the intervention condition with higher levels of support at baseline were more likely to maintain that support. Marziali and Donahue (2006) did not find a difference between intervention and control groups in relation to perceived social support at follow up. Torp et al. (2008) found increases in social contacts and social support at follow up. This is perhaps not a surprising finding given that a significant part of the intervention involved introducing computer novices to the internet.

### *Positive aspects of caregiving*

Two studies used measures of the positive elements of caregiving (Beauchamp et al., 2005; Glueckauf & Loomis, 2003) and one of these studies also looked at the demands and rewards of caring (Glueckauf & Loomis, 2003). These studies received quality scores of 20 and 10. The better quality study (Beauchamp et al., 2005) found favourable results in relation to the positive elements of caring, but the lower quality study (Glueckauf & Loomis, 2003) did not.

### *Carer self-efficacy*

A lower quality study, with a quality score of 10 (Glueckauf & Loomis, 2003), used the Caregiving Self-Efficacy scale. This study found that carers reported pre to post improvements on all three subscales of this measure. A higher quality study, with a score of 20 (Beauchamp et al., 2005) asked participants six “self-efficacy questions” and found that compared to the control group, the treatment group reported greater gains with respect to self-efficacy.

### *Programme impact measures and composite measures*

Four studies used items or measures that asked participants how the intervention had changed aspects of caring for them (Gallagher-Thompson et al., 2010; Lewis et al., 2010; Magnusson et al., 2005; Torp et al., 2008). In this review, these measures are referred to as programme impact measures. One additional study used a 16-item knowledge questionnaire (Rosen et al., 2003). All of these studies found positive effects on these measures. For the most part, the studies that used these measures were of poorer quality, receiving quality scores of 18, 9, 5, 11 and 8 respectively. This is, in part, because studies that use such measures as their only outcome measure cannot score highly.

Lewis et al. (2010) was one of two studies that only used a programme impact measure. Participants generally endorsed finding the intervention to be educational, convenient, useful and interesting. Lewis et al. (2010) generally did not find any significant relationships between demographic data and responses, apart from a low correlation between age and the caregiving scale; as age increased, score on the caregiving scale decreased, indicating less perceived benefit from the intervention.

In Torp et al.'s (2008) study, it was found that at follow-up, carers reported less need for information about the cared-for person's illness and caring. However, whether this knowledge would have equated to an increase in ability or confidence in caring for the person cannot be established.

Rosen et al. (2003) used a 16-item knowledge questionnaire before and after a computer-based education intervention for family members of people with dementia who were nursing home residents. They found that knowledge of key principles of dementia care improved after the intervention. It is worth noting, however, that the mean score on the knowledge questionnaire increased by 2.3 items. While this was statistically significant, it is worth reflecting on what such an increase would mean in practice. This issue of clinical significance versus statistical significance is pertinent for many of the studies in this review, and is considered in the Discussion below.

## **Discussion**

This review aimed to look at the effectiveness of computer-mediated interventions for informal carers of people with dementia. Fifteen papers describing 13 studies met inclusion criteria. Interventions were multifaceted and considerably varied, with a range of different outcome measures, and both of these factors make

direct comparison of studies difficult. The challenge of comparing studies and interventions has been raised by a number of previous researchers investigating support for carers of people with dementia (for example, Wu et al., 2009). All of the studies appraised in this review found some positive effects of the intervention evaluated, although a number of these studies were not of good quality. In two cases, positive results were only found following post hoc-tests (Chiu et al., 2009; Finkel et al., 2007), and in three cases such results were from unstandardised programme impact questionnaires or knowledge tests (Lewis et al., 2010; Magnusson et al., 2005; Rosen et al., 2003).

Having said this, the most commonly measured variables were carer burden/stress and depression. In general, higher quality studies found that interventions did have an effect on these variables. Two higher quality studies also found that anxiety was reduced following intervention. Positive aspects of caring may also be increased through these interventions as may carer self-efficacy. There are mixed results in relation to social support, and physical aspects of caring do not seem to be affected. Programme impact measures indicate general acceptability of these interventions.

Due to the fact that interventions were multi-component and complex in nature, it is difficult to disentangle the effects of individual intervention components and provide an overall picture of which intervention components or combinations were more effective than others. Indeed, a large range of factors have the potential to influence the effectiveness of interventions, including the intensity and duration of the intervention, carer characteristics and the outcomes selected (Cooke, McNally, Mulligan, Harrison, & Newman, 2001).

Two studies (Finkel et al., 2007; Mahoney et al., 2003) found that intervention effects were moderated by certain baseline characteristics of participants. Mahoney et al. (2003) found that there were only intervention effects for those participants who had low to mid levels of mastery at baseline: their depression, anxiety and bother scores all decreased. Similarly, Finkel et al. (2007) found that as baseline depression increased, carers in the intervention group demonstrated greater improvements in depression.

One study (Beauchamp et al., 2005) conducted a dose-response analysis, which revealed that more time spent viewing the intervention programme was associated with greater change in outcome. This highlights the need for carers to be self-motivated in order to benefit from some computer-mediated interventions, particularly those that do not involve “checking in” in some way with a professional.

Two relatively high quality studies (Eisdorfer et al., 2003; Mahoney et al., 2003) considered the differential effects of interventions according to carer ethnicity and carer-care recipient relationship. Both found statistically significant results. These differential findings caution against generalising results of research too widely. Previous research has suggested that the carer’s gender and relationship to the person that they are caring for can have an impact on the effect of caring on the carer. For example, there is some evidence that spousal carers experience higher levels of stress and depression (George & Gwyther, 1986). Eisdorfer et al. (2003) and Mahoney et al.’s (2003) findings also highlight the need for such factors to be considered in the design of interventions for carers of people with dementia, in order that they are as effective as possible for their target populations. Multimedia interventions are arguably better suited to being tailored to the user than more traditionally delivered interventions.

## **Methodological issues**

There was a range of study designs, with six of the 13 studies using a randomised controlled design. In theory, this allowed for more robust conclusions to be made from their findings, although no study reported a power calculation and a number of studies were underpowered.

Some studies were not clear on why certain areas were evaluated. More detail regarding how intervention aims mapped onto outcome measures would have been useful in a number of studies. A wide range of measures was used. Many were standardised and had good psychometric properties, but some were composite measures created using items from a range of other measures, and some were created specifically for the study. The only measures that were used in more than two studies were the CES-D, which was used in seven studies and was the only depression measure used across all the studies, and the RMBPC, which was used in four studies. Again, the range of measures used made direct comparison of studies difficult, and poor quality measures can limit the scope of conclusions that can be made.

How to measure the “success” of carer support interventions is an area that has received some attention. Magnusson et al. (2005, p.695) summarise this work by noting that “there have been calls for clearer conceptual links between the support provided and the measures used to ‘indicate’ its success..., with outcomes being meaningful to family carers..., and reflecting what is reasonable and modifiable within a given care-giving context”. This includes whether the measure used is an appropriate tool given the aims of the intervention. For example, it seems to be the case that there is something of a mismatch between Rosen et al.’s (2003) intervention aims, and the measure used to see whether the intervention met those aims. The reported aim of the intervention was to enhance family participation in nursing home

care. While the intervention demonstrated an increase in family members' knowledge about dementia, this does not necessarily translate to enhanced participation in their relative's care.

Follow-up periods were often short, and for the majority of studies follow-up was only completed at the termination of the intervention. This means that the longer-term effects of computer-mediated interventions for carers of people with dementia are currently relatively unknown.

Almost all studies considered the statistical significance of their findings, but none considered their clinical significance. It would be useful to know, for example, how many participants who received an intervention moved from scores indicating clinical depression to scores indicating no clinical depression. While a certain drop in score on a measure indicates that overall, participants' scores were statistically significantly lower, it may not mean much clinically for those individuals.

The evaluation of studies using Downs and Black's (1998) quality assessment checklist provided a framework with which to appraise the strengths and limitations of studies and enabled a comparison of the quality of studies according to the domains that the tool covered. This meant that the results and conclusions drawn from studies could be considered within the context of study quality. Such a tool inevitably has limitations, however. For example, each item, with the exception of item 5, is scored 0 or 1 and arguably some of the areas covered by the tool are more important contributions to a study's quality than others. This, however, is not reflected in this instrument.

### **Clinical implications and future research**

Computer-mediated interventions for informal carers of people with dementia is a growing area of carer support and offers a range of potential benefits compared

to interventions that are delivered through more traditional mediums. This review suggests that overall evidence for computer-mediated interventions for carers of dementia is mixed, but generally positive. This suggests that it would be beneficial to carers, and also to services – in terms of reaching more carers as well as potential cost saving implications – for this medium of intervention to be developed so that more individuals can benefit. As in-home computer use becomes increasingly ubiquitous, the viability of computer-mediated interventions increases, and the cost to service providers decreases since increasing numbers of carers already have the requisite equipment in their homes. More research is, however, required in order to ensure that such interventions are as effective as possible. In particular, there is a need for well designed, methodologically rigorous studies that have sufficient statistical power. Research needs to consider the effects of interventions on people of different ethnicities and carer-care recipient relationships, as there is evidence that differential effects exist between groups. Future research would benefit from longer follow-up periods. It is also important that outcome measures are carefully considered and closely linked to the aims of interventions in order that their “effectiveness” can be properly evaluated.

Although it was beyond the scope of this review to consider the qualitative components of studies, information gathered from interviews with carers who have used computer-mediated interventions offers an important supplement to quantitative outcome measures. It provides deeper insight into carers’ experiences of using the interventions, and is able to go beyond measurement of symptom reduction and tap into factors, such as feeling supported, that are of great importance to carers. Future research into computer-mediated interventions for carers of people with dementia would benefit from being multi-method in its approach.

Caring for a relative or friend with dementia is associated with a range of physical and mental health risks. Computer-mediated interventions offer a new way to support informal carers of people with dementia, and these interventions have a range of potential advantages compared to more traditional interventions.

## References

- Alzheimer's Society (2011). *Alzheimer's Society: Statistics*. Retrieved 21 July 2011 from:  
[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=341](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=341)
- American Psychological Association (2012). *The Revised Memory and Behavior Problems Checklist*. Retrieved from:  
<http://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/memory-behavior.aspx>, 20<sup>th</sup> November 2012
- Bank, A.L., Argüelles, S., Rubert, M., Eisdorfer, C. & Czaja, S.J. (2006). The value of telephone support groups among ethnically diverse caregivers of persons with dementia. *The Gerontologist*, 46,1, 134-138.
- Beauchamp, N., Irvine, A.B., Seeley, J. & Johnson, B. (2005). Worksite-based internet multimedia program for family caregivers of persons with dementia. *The Gerontologist*, 45,6, 793-801.
- Chiu, T.M.L. & Eysenbach, G. (2010). Stages of use: Consideration, initiation, utilization, and outcomes of an internet-mediated intervention. *BMC Medical Informatics and Decision Making*, 10, 73-83.
- Chiu, T., Marziali, E., Colantonio, A., Carswell, A., Gruneir, M., Tang, M. & Eysenbach, G. (2009). Internet-based caregiver support for Chinese Canadians taking care for a family member with Alzheimer Disease and related dementia. *Canadian Journal on Aging*, 28, 4, 323-336.
- Colantoni, A., Cohen, C. & Pon, M. (2001). Assessing support needs of caregivers of persons with dementia: Who wants what?. *Community Mental Health Journal*, 37,3, 231-243.

- Cooke, D.D., McNally, L., Mulligan, K.T., Harrison, M.J.G & Newman, S.P. (2001). Psychosocial interventions for caregivers of people with dementia: A systematic review. *Aging and Mental Health*, 5, 2, 120-135.
- Devins, G.M., Orme, C.M., Costello, C.G., Brink, Y.M., Frizzell, B., Stam, H.J. & Pullin, W. (1988). Measuring depressive symptoms in illness populations: Psychometric properties of the Center for Epidemiologic Studies Depression (CES-D) Scale. *Psychology and Health*, 2, 2, 139-156.
- Downs, S.H. & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology and Community Health*, 52, 377-384.
- Eisdorfer, C., Czaja, S.J., Loewenstein, D.A., Rubert, M.P., Argüelles, S., Mitrani, V.B. & Szapocznik, J. (2003). The effect of a family therapy and technology-based intervention on caregiver depression. *The Gerontologist*, 43, 4, 521-531.
- Finkel, S., Czaja, S.J., Schulz, R., Martinovick, Z., Harris, C. & Pezzuto, D. (2007). E-care: A telecommunications technology intervention for family caregivers of dementia patients. *American Journal of Geriatric Psychiatry*, 15, 5, 443-448.
- Galinsky, M.J., Schopler, J.H. & Abell, M.D. (1997). Connecting group members through telephone and computer groups. *Health and Social Work*, 22, 181-188.
- Gallagher-Thompson, D. & Coon, D.W. (2007). Evidence-based psychological treatments for distress in family caregivers of older adults. *Psychology and Aging*, 22,1, 37-51.

- Gallagher-Thompson, D., Wang, P-C., Liu, W., Cheung, V., Peng, R. China, D. & Thompson, L.W. (2010). Effectiveness of a psychoeducational skill training DVD program to reduce stress in Chinese American dementia caregivers: Results of a preliminary study. *Aging and Mental Health, 14*, 3, 263-273.
- Gant, J.R., Steffen, A.M. & Lauderdale, S.A. (2007). Comparative outcomes of two distance-based interventions for male caregivers of family members with dementia. *American Journal of Alzheimer's Disease and Other Dementias, 22*, 2, 120-128.
- George, L.K. & Gwyther, L.P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *The Gerontologist, 26*, 3, 253-259.
- Glueckauf, R.L, Ketterson, T.U., Loomis, J.S. & Dages, P. (2004). Online support and education for dementia caregivers: Overview, utilization, and initial program evaluation. *Telemedicine Journal and e-Health, 10*, 2, 223-232.
- Glueckauf, R.L. & Loomis, J.S. (2003). Alzheimer's caregiver support online: Lessons learned, initial findings and future directions. *NeuroRehabilitation, 18*, 135-146.
- Glueckauf, R.L, Sharma, D., Davis, W.S., Byrd, V., Stine, C., Jeffers, S.B., Massey, A., Wesley, L.M., McIntyre, V. & Martin, C. (2007). Telephone-based cognitive-behavioral intervention for distressed rural dementia caregivers: Initial findings. *Clinical Gerontologist: The Journal of Aging and Mental Health, 31*, 1, 21-41.
- Lewis, M., Hobday, J.V. & Hepburn, K.W. (2010). Internet-based program for dementia caregivers. *American Journal of Alzheimer's Disease and Other Dementias, 25*, 8, 674-679.

- Mahoney, D., Tarlow, B.J. & Jones, R.N. (2003). Effects of an automated telephone support system on caregiver burden and anxiety: Findings from the REACH for TLC intervention study. *The Gerontologist*, 43, 4, 556-567.
- Marziali, E. & Donahue, P. (2006). Caring for others: Internet video-conferencing group intervention for family caregivers of older adults with neurodegenerative diseases. *The Gerontologist*, 46, 3, 398-403.
- Magnusson, L., Hanson, E. & Nolan, M. (2005). The impact of information and communication technology on family carers of older people and professionals in Sweden. *Aging and Society*, 25, 693-713.
- Marziali, E. & Garcia, L.J. (2011). Dementia caregivers' responses to 2 internet-based intervention programs. *American Journal of Alzheimer's Disease and Other Dementias*, 26, 1, 36-43.
- Michon, A., Weber, K., Rudhard-Thomazic, V. & Giannakopoulos, P. (2005). Dynamic process of family burden in dementia caregiving: A new field for psychotherapeutic intervention. *Psychogeriatrics*, 5, 48-54.
- Powell, J., Chiu, T., & Eysenbach, G. (2008). A systematic review of networked technologies supporting carers of people with dementia. *Journal of Telemedicine and Telecare*, 14,3, 154-156.
- Pusey, H. & Richards, D. (2001). A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia. *Aging and Mental Health*, 5,2, 107-119.
- Rosen, J., Mittal, V., Mulsant, B.H., Degenholtz, H., Castle, N. & Fox, D. (2003). Educating the families of nursing home residents: A pilot study using a computer-based system. *Journal of the American Medical Directors Association*, 4, 128-134.

- Schulz, R. & Beach, S.R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *The Journal of the American Medical Association*, 282,23, 2215-2219.
- Schulz, R. & Martire, L.M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry*, 12,3, 240-249.
- Schulz, R., O'Brien, A.T., Bookwala, J. & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates and causes. *The Gerontologist*, 35,6, 771-791.
- Sörensen, S., Pinquart, M. & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 42, 356-372.
- Stoltz, P., Udén, G. & Willman, A. (2004). Support for family carers who care for an elderly person at home – a systematic literature review. *Scandinavian Journal of Caring Sciences*, 18,2, 111-119.
- Thompson, C.A., Spilsbury, K., Hall, J., Birks, Y., Barnes, C. & Adamson, J. (2007). Systematic review of information and support interventions for caregivers of people with dementia. *BMC Geriatrics*, 7, 18.
- Torp, S., Hanson, E., Hauge, S., Ulstein, I. & Magnusson, L. (2008). A pilot study of how information and communication technology may contribute to health promotion among elderly spousal carers in Norway. *Health and Social Care in the Community*, 16, 1, 75-85.
- Vitaliano, P.P., Young, H.M., Russo, J., Romano, J. & Magana-Amato, A. (1993). Does expressed emotion in spouses predict subsequent problems among care recipients with Alzheimer's disease?. *The Journals of Gerontology*, 48, 202-209.

White, M. & Dorman, S.M. (2001). Receiving social support online: Implications for health education. *Health Education Research*, 16, 6, 693-707.

Wilz, G. & Schinköthe, D. (2011). Goal attainment and treatment compliance in a cognitive-behavioral telephone intervention for family caregivers of persons with dementia. *The Journal of Gerontopsychology and Geriatric Psychiatry*, 34,3, 115-125.

Wu, Y., Faucounau, V., de Rotrou, J., Riguet, M. & Rugaud, A-S. (2009).

Intervention psychosociale auprès d'aidants familiaux de patients atteints de la maladie d'Alzheimer et technologies de l'informaton et de la communication: Une revue de la littérature / Information and communication technology interventions supporting carers of people with Alzheimer's Disease: A literature review. *Psychologie & NeuroPsychiatrie du Vieillissement*, 7,3, 185-192.

## **Part 2: Empirical Paper**

### **The impact of an online support forum for carers of people with dementia**

## **Abstract**

**Aims:** This research evaluated Talking Point, the Alzheimer's Society's online support forum for carers of people with dementia. It was hypothesised that users would show reductions in anxiety and depression and that the magnitude of such changes would be correlated with the amount of forum usage. Relationship quality with the person with dementia was also investigated.

**Methods:** The study used a mixed-methods approach. Sixty-one new users of Talking Point completed measures of anxiety (GAD-7), depression (PHQ-9), and quality of relationship with the person with dementia (SQCRC), at baseline and again after 12 weeks of forum usage. In addition, eight participants were interviewed about their experiences of using Talking Point.

**Results:** There was an improvement in the quality of the relationship with the person with dementia (SQCRC;  $p=0.003$ ). There was no change in users' depression (PHQ-9) or anxiety (GAD-7) over the 12 week study period. Interview participants reported a range of positive experiences and benefits from using Talking Point. Limited negative experiences were also reported.

**Conclusions:** Many of the reported experiences and benefits are unique to online peer support. Further research into online peer support for carers of people with dementia is needed in order that such support can be designed so that carers derive maximum benefit.

## **Introduction**

The wellbeing of informal carers of people with dementia is an important public health issue. There are currently about 750 000 people in the UK with dementia (Alzheimer's Society, 2011). Some live in residential care, but many are cared for at home by a relative or friend. Caring for an elderly relative with disability is burdensome and stressful, and negatively affects the carer's social, family and professional life (Schulz, O'Brien, Bookwala & Fleissner, 1995), and the risk of anxiety and depressive disorders is increased (Schulz & Martire, 2004). The combination of loss, the physical demands of caregiving, prolonged distress, and biological vulnerabilities of older carers may also compromise their physical health (Schulz & Martire, 2004) and mortality (Schulz & Beach, 1999). Thus, their ability to function as carers can be diminished.

### **Mutual support**

There is a range of ways in which individuals in distress can be helped, and there is a range of people who can provide this help. Helping can be conceptualised on a formal-informal continuum, with trained professionals such as psychologists at the formal end, through to "helping by ordinary people in everyday settings" (Barker & Pistrang, 2002, p.362) at the informal end. Also at the more informal end of the continuum are mutual support groups. These are run principally by the members themselves and exist for a large number of difficulties, covering mental health problems such as depression and anxiety (Pistrang, Barker & Humphreys, 2008) as well as physical health problems such as cancer (Taylor, Falke, Shoptaw & Lichtman, 1986) and HIV (Kendall, 1992). Groups also exist for family members and carers of those suffering from physical or mental health problems (see, for example, Solomon, Pistrang & Barker, 2001).

Mutual support groups have a number of potential benefits. These include: “promoting a psychological sense of community, providing emotional support, providing role models, conveying a powerful ideology, providing information, offering ideas about ways of coping, giving the opportunity to help others, providing social companionship, and promoting a sense of mastery and control” (Solomon et al., 2001, p.114). Currently, however, evidence for the benefits of mutual support is limited when compared to the evidence for formal helping (Davison, Pennebaker & Dickerson, 2000; Pistrang et al., 2008).

The rise of the internet and other networked technologies has provided a new medium through which mutual support groups can be organised. People are no longer restricted to meeting face-to-face, but are now able to support one another even from physically distanced locations, twenty four hours a day, seven days a week. This is particularly helpful for individuals who are physically isolated or experiencing uncommon problems (White & Dorman, 2001).

### **Support for carers of people with dementia**

There exists a range of support interventions for carers of people with dementia. One type of support intervention is mutual support, and a small amount of research into mutual support for carers of people with dementia has been undertaken. For example, Pillemer and Sutor (2002) conducted a randomised controlled trial of one-to-one face-to-face peer support for new carers of people with Alzheimer’s Disease, in which social support enhancement was isolated as the only intervention mechanism without simultaneously providing education, counselling or direct services. The outcomes were carer depression, as measured by the Center for Epidemiologic Studies Depression Scale, and carer self-esteem, measured by the Rosenberg Self-Esteem Scale. Their results suggested that social support alone was

not a sufficient intervention to improve the experience of caregivers, and that perhaps it was necessary, but not sufficient on its own, to effect change. They concluded that multicomponent interventions were necessary to achieve significant intervention effects and that peer support enhancement itself did not bring about significant benefits. These results are surprising given that one underlying factor that leads to negative outcomes in carers is a deficit in social support (Schulz et al., 1995). Indeed, carers of people with dementia frequently report feelings of isolation and inadequate social support (Stoltz, Udén & Willman, 2004). However it may be that the nature of caring for someone with Alzheimer's Disease is so distressing that only comprehensive, multicomponent interventions would bring about effects. One-to-one peer support is a different type of mutual support to a large group or forum, and it is inevitable that a larger group will collectively have more knowledge and be able to offer more advice to one another. Carers may therefore find groups more useful in that regard. Indeed, Stoltz et al.'s (2004) review found that carers fear social isolation and wish to network in groups.

There is a growing body of research into interventions for carers of people with dementia that are delivered in non-traditional ways. These are primarily computer-based but also include, for example, telephone interventions. Online support for carers of people with dementia was an early application of the internet (see, for example, Brennan, Moore & Smyth, 1995). There now exists a range of multifaceted interventions with elements of networked support (Powell, Chiu & Eysenbach, 2008). Generalisable conclusions are difficult, however, because of the multiple and varied components within each intervention (Eysenbach, Powell, Englesakis, Rizo & Stern, 2004).

There has been limited research specifically looking at online mutual support for carers of people with dementia, and this has generally focused on the content of messages and posts. White and Dorman (2000) examined the content and themes of messages posted on a public Alzheimer mailgroup over a 20 day period. They found that members used the mailgroup to find and proffer information, share experiences and opinions, and provide encouragement. Brennan et al. (1995) analysed the use of ComputerLink, an online support mechanism that included, but was not limited to, a public bulletin board, and found that the board contained both information and support-seeking messages.

Research into networked technologies as a medium for supporting carers of people with dementia has so far primarily focused on changes in carers' outcome measures, such as caregiver burden and anxiety (Mahoney, Tarlow & Jones, 2008), comparing their scores before and after the intervention. Some of this research evaluates interventions that include mutual support, but are not limited to it. Studies in Powell et al.'s (2008) systematic review looked at interventions that included, for example, an electronic encyclopaedia, an expert forum, and therapist-facilitated video conferencing support. There appears to be little research that looks exclusively at online mutual support for carers of people with dementia, or research that attempts to understand more about how carers find online mutual support to be helpful.

### **Present research**

Online mutual support groups for carers of people with dementia provide a number of potential advantages compared to more traditional support mechanisms. These include logistical advantages of carers being able to access support from their homes, and cost advantages to service providers. In order to make the best use of this technological resource, and to ensure that support networks are designed so that

carers gain maximum benefit, it is important to understand how carers experience the groups, including what they find to be more and less helpful.

The present research was a mixed-methods evaluation of Talking Point, the Alzheimer's Society's online forum for carers of people with dementia. The quantitative component involved baseline and 12 weeks post-usage measurement of new forum users' depression, anxiety, and quality of relationship with the care recipient. The qualitative component involved semi-structured interviews with new users of Talking Point. Previous research has identified depression and anxiety as more common in carers of people with dementia (Schulz & Martire, 2004). Carer depression and anxiety are widely investigated in carer research, and research into networked technologies supporting carers of people with dementia has found moderate effects on improving carer anxiety and depression (see, for example, Powell et al., 2008). In addition, the carer-patient relationship can affect the progress of the dementia, with evidence that high levels of expressed negative emotion (such as criticism and hostility) are predictive of increased negative behaviours in the person with dementia over time (Vitaliano, Young, Russo, Romano & Magana-Amato, 1993). Carer anxiety, depression, and quality of the relationship with the person being cared for, are therefore pertinent areas to investigate in the evaluation of Talking Point.

It was hypothesised that after 12 weeks of forum usage:

1. Users' anxiety and depression would decrease.
2. The magnitude of this effect would be correlated with level of forum usage.

Changes in the quality of the relationship with the person with dementia were also examined. No hypotheses were made in relation to this variable; although there

is some evidence that over a longer time period the relationship quality might deteriorate (see, for example, Gallagher-Thompson, Dal Canto, Jacob & Thompson, 2001; de Vugt et al., 2003), it would be anticipated that the forum might increase the quality of the relationship. The likely effect is therefore that the quality of the relationship will remain approximately stable.

Qualitative interviews examined in greater depth participants' experiences of being on the forum and possible positive or negative outcomes.

## **Method**

### **Setting**

This research was primarily conducted online, with participants accessing the first survey through a link on the Alzheimer's Society's Talking Point homepage. There were also eight follow-up face-to-face and telephone interviews.

### **Ethical considerations**

Ethical approval was obtained from the University College London Ethics Committee (see Appendix 2).

### **Intervention**

Talking Point is the Alzheimer's Society's online forum for carers of people with dementia (<http://forum.alzheimers.org.uk/forum.php>). Its webpage describes it as "an online support and discussion forum, for anyone affected by dementia. It's a place to ask for advice, share information, join in discussions and feel supported". The forum is very well used; on 21 July 2011 there were 666 active members in the forum, and at the time of visiting (16:45), there were 274 users online (42 members and 242 guests). It contains a number of different areas, including "Support for people with dementia and their carers", which is the most active part of the forum. This part of the forum contains a number of discussion threads, which are started by

members and responded to by other members. These discussion threads cover a wide range of issues, some practical, for example a member seeking advice about bed rails, and some emotional, for example, a member expressing distress following a difficult situation. There is a private messaging function if members wish to contact one another away from the public forum. Anybody can view the forum, but in order to contribute to discussion threads or message other users, individuals must register as members. This is without financial cost. Talking Point also has a number of volunteer moderators. Please see Appendix 3 for a sample screenshot of a discussion thread.

### **Participants**

The participants in were new users of Talking Point who were carers of people with dementia. Inclusion criteria, which were specified on the information sheet of the online survey, were that participants had to be:

1. A new user of Talking Point on their first visit to the forum
2. An “informal carer” for a relative or friend with dementia (i.e. unpaid)
3. Involved in a significant amount of the care of this person, for example the main carer, or heavily involved in the care, e.g. the daughter of a man with dementia whose wife is the main carer, but nonetheless the daughter is heavily involved in her father’s care.
4. Over 18 years old
5. An English speaker

Additionally, participants were eligible for the qualitative interview if:

1. They ticked the box in the survey at baseline saying they were interested in being interviewed
2. They completed the survey at 12 weeks

3. Their usage data indicated that they had visited Talking Point at least six times over the 12 week study period

#### *Participant numbers and response rate*

One hundred and twenty-eight participants completed the first survey between 25 July 2012 and 9 January 2013. It is not possible to ascertain precisely what percentage of potential participants chose to take part in the research, although an estimate is possible; in the six months between 1 July 2012 and 31 January 2013, 4177 new users registered on Talking Point, suggesting that the percentage of potential participants who took part in the research was low (approximately 3%). It is also possible that some people who took part in the research had already registered prior to this date, and that others never registered as they simply visited the forum to read other people's posts, for which membership is not required. Figure 1 shows numbers of participants at each stage in the research process. Six participants were not sent the survey at 12 weeks; five of them gave responses at baseline suggesting that they were not eligible for the research, and one gave an email address that did not work. Three participants said that the person with dementia had died during the study period, so they were also not included in the study. Of the 119 eligible participants who completed the survey at baseline, 61 (51%) completed it at 12 weeks.

#### *Participant demographics*

A total of 119 eligible participants completed the survey at baseline. There was a limited amount of missing data, which included two responses for participant sex, one for age, eight missing or ambiguous responses for educational level, and eight missing or ambiguous responses for number of months caring. See Table 1 for participant demographic information. The information in Table 1 has excluded the

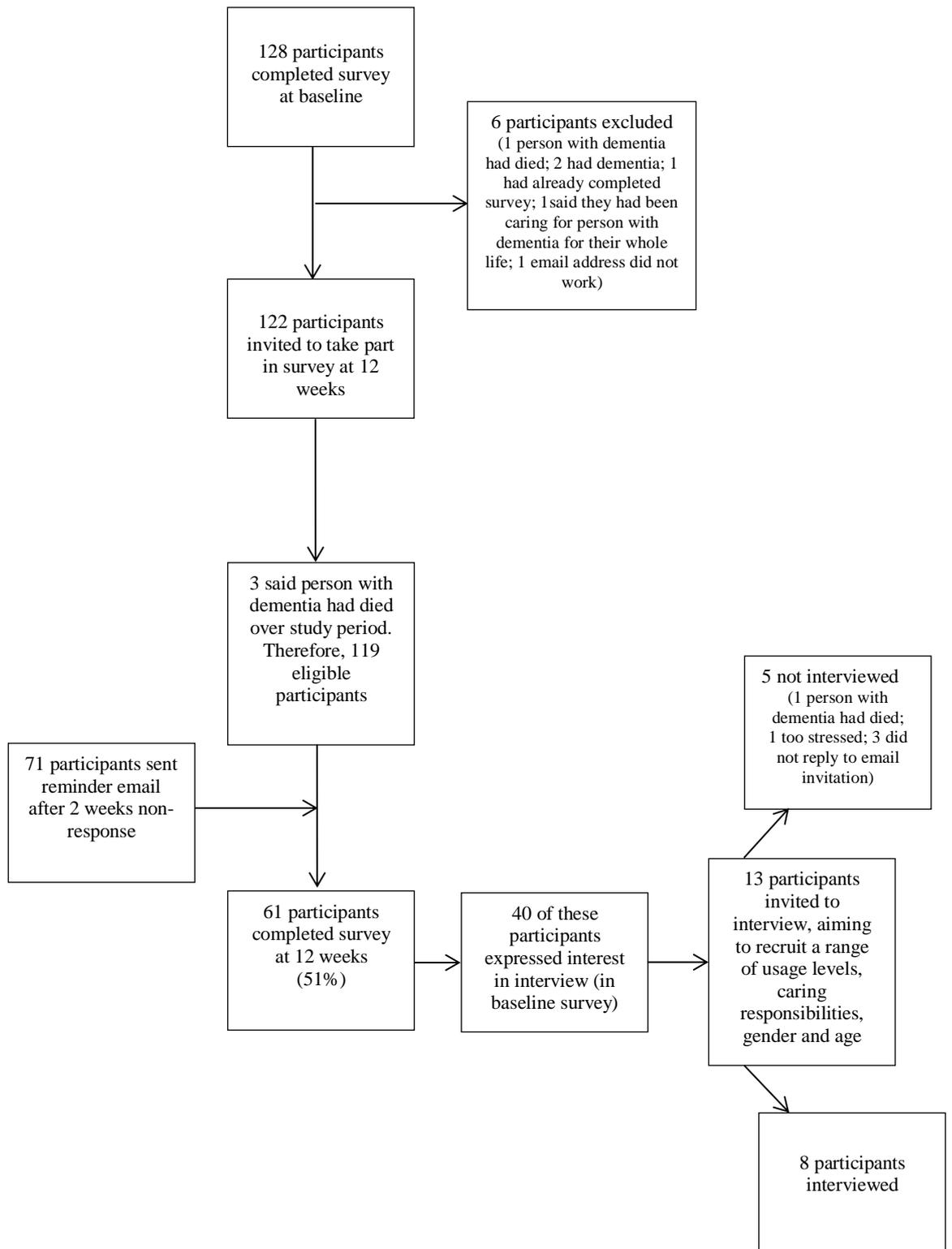


Figure 1: Participant flow chart

Table 1: Participant information

	Range	<i>M (SD)</i>
Age in years	22-86	56 (11.29)
Number of months caring	0-408	44 (56.94)
	<i>n</i>	%
Sex		
Female	99	85
Male	18	15
Ethnicity		
White British	112	94
White Other	4	3
Employment status		
Employed	58	49
Unemployed	19	16
Retired	42	35
Educational level		
Primary school	7	6
GCSEs/equivalent	22	20
A levels/equivalent	16	14
University degree	39	35
Higher degree/equivalent	18	16
Other	9	8
Person being cared for <sup>a</sup>		
Father	22	18
Mother	45	38
Partner	38	32
Grandparent	3	3
Aunt or uncle	3	3
Sibling	5	4
Mother or father in law	6	5
Neighbour or friend	1	1
Ex-partner	1	1
Brother in law	1	1
Formal support received		
GP	24	20
Mental health worker or counsellor	6	5
Another health or social care professional	27	23
Memory clinic	22	19
Other/not specified	8	7
No formal support	55	46
Informal support received		
Friends and/or family	49	41
Religious organisations	2	2
Recreational groups	1	1
Charities, helplines, or forums	12	10
Other/not specified	5	5
No informal support	51	43

<sup>a</sup>Note that figures total more than 100% as six participants reported that they were caring for more than one person

missing data and percentages relate to those participants who responded. Table 2 provides information about interview participants.

#### *Power calculation*

A recent systematic review (Powell et al., 2008, p.154) found that while results were inconsistent, networked technology interventions for carers of people with dementia had “moderate effects on improving carer stress and depression”. Assuming a medium-small effect size (0.35), a sample size of 67 is required for this analysis (Faul, Erdfelder, Buchner & Lang, 2009). The actual sample size achieved in this study was 61.

#### **Procedure**

New users of Talking Point were invited to take part in the research through an advertisement on the Talking Point homepage (Appendix 4). From there, they were able to click on a link to the survey. This included an information sheet (Appendix 5) and a consent form (Appendix 6). A box on the consent form had to be checked before they were able to proceed with the research. During the recruitment phase, an email was also sent to members of Talking Point to alert them to the research, and the research was promoted on the Alzheimer’s Society’s Facebook and Twitter pages.

At baseline, participants completed the three standardised measures (SQCRC, GAD-7, PHQ-9). They also answered demographic questions and questions about their role as a carer.

Table 2: Interviewee information

Participant number	Demographic information	Caring situation
1	Female 51 years old White British	Caring for husband (53 years old) who has frontotemporal dementia. Participant and her husband live together. Caring for approximately 1yr 9 months at time of interview.
2	Female 48 years old White British	Caring for mother who has a mixed diagnosis of vascular dementia and Alzheimer's Disease. Mother does not live with participant. Caring for approximately 2yrs 5 months at time of interview.
3	Female 43 years old White British	Caring for father who has dementia and lives locally. Caring for approximately 2yrs 4 months at time of interview.
4	Male 70 years old White British	Caring for wife who has vascular dementia. Participant and his wife live together. Caring for approximately 2yrs 9 months at time of interview.
5	Male 84 years old White British	Caring for wife who has Alzheimer's Disease. Caring for approximately 2yrs 6 months at time of interview. Wife moved into care home one year ago.
6	Female 69 years old White British	Does not consider herself a carer as husband is in the early stages of Alzheimer's Disease and does not require significant levels of support. At time of interview, it was approximately 2yrs 5 months since memory problems began.
7	Female 63 years old White British	Caring for mother in law who lives locally and has dementia. Caring for approximately 1yr at time of interview.
8	Female 61 years old White British	Caring for husband who has dementia. Participant and her husband live together. Caring for approximately 1yr 6 months at the time of interview.

Twelve weeks after completing the first survey, participants were emailed a link to complete the three standardised measures again, as well as some questions about their use of the forum over the 12 week period. Those who did not complete the second survey within two weeks of being sent the email were sent a reminder email.

When completing the first online survey, participants were asked whether they would be interested in taking part in an interview about their experiences of using Talking Point. It was made clear that this was an optional extra part to the

research. Interview participants were selected in order to try to sample a range of different users, in terms of their sex, age, person they were caring for, and length of time they had been caring for. Only participants who reported that they had used Talking Point more than six times were invited to interview. This was in order to ensure that they had experience of Talking Point to draw on during the interview. Interview participants were given a £10 gift voucher to recognise the time that they had taken to participate in the research.

In accordance with the study risk protocol, those whose scores from the first or the second survey on the PHQ-9 and/or the GAD-7 placed them in the “severe” range for depression or anxiety were emailed and advised that they may wish to make contact with their GP (see Appendix 7 for email text). A total of 49 participants were sent this email.

## **Measures**

Participants completed three standardised measures at baseline and again after 12 weeks. At baseline they also answered a number of demographic questions and questions related to their role as a carer (see Appendix 8).

*The scale for the quality of the current relationship in caregiving 14-item version* (SQCRC-14; Spruytte, Van Audenhove & Lammertyn, 2000; see Appendix 9). This questionnaire asks carers about their relationship with the person that they are caring for. Sample items are: “My relative and I often spend time together in an enjoyable way” and “My relative often annoys me”. Items are scored on a five point scale ranging from 1 = “Totally disagree” to 5 = “Totally agree”. “Warmth and affection” items are scored positively and “conflict and criticism” items are reverse scored. A higher score implies the presence of warmth and affection and the absence of conflict and criticism in the relationship.

Spruytte, Van Audenhove, Lammertyn and Storms (2002) report an internal consistency of .82. They dichotomised responses, using the median of the range of possible scores (range: 14-70) to differentiate between “good” relationships (score >42) and “poor” relationships (score ≤42). The measure has promising reliability and face validity, but has had little psychometric investigation.

*Generalised Anxiety Disorder Assessment (GAD-7; Spitzer, Kroenke, Williams & Löwe, 2006; see Appendix 10).* The GAD-7 is a seven item measure of anxiety. It asks participants “over the last two weeks, how often have you been bothered by any of the following problems”, for example, “being so restless that it is hard to sit still”. Each item has four possible responses ranging from 0 = “Not at all” to 3 = “Nearly every day”. Scores of five or over are considered to suggest mild anxiety, scores of 10 or over moderate anxiety, and scores of 15 or over severe anxiety (Spitzer et al., 2006).

The GAD-7 has sensitivity of 89% and specificity of 82% for diagnosing generalised anxiety disorder with a cut-off score of 10 (Spitzer et al., 2006). Kroenke, Spitzer, Williams, Monahan and Löwe (2007) found that the GAD-7 was almost as effective at detecting social anxiety, panic disorder, and posttraumatic stress disorder. In a community sample of 5030 people aged over 14 years old in Germany, Löwe et al. (2008) found the GAD-7 to be a reliable and valid measure for anxiety in the general population. They found that the measure had a unidimensional structure in different groups of age and gender. Its internal consistency was .89. Approximately 5% of the sample scored 10 or more on the GAD-7, and approximately 1% scored 15 or more.

*Patient Health Questionnaire (PHQ-9; Kroenke, Spitzer & Williams, 2001; see Appendix 11).* The PHQ-9 is a nine item measure of depression, asking

participants “over the last two weeks, how often have you been bothered by any of the following problems”, for example, “feeling tired or having little energy”. Each item has four possible responses ranging from 0 = “Not at all” to 3 = “Nearly every day”. Scores of five or more suggest mild depression, 10 or more suggest moderate depression, 15 or more suggest moderately severe depression, and scores of 20 or more suggest severe depression.

The PHQ-9 has sensitivity of 88% and specificity of 88% for diagnosing depression in with a cut-off score of 10 (Kroenke et al., 2001). A German community sample of 2066 people over the age of 14 years old (Martin, Rief, Klaiberg & Braehler, 2006) suggested convergent validity; PHQ-9 depression severity was strongly associated with scores on the short version of the Beck Depression Inventory ( $r=.73, p<.0001$ ). In a Scottish primary care study, Cameron, Crawford, Lawton and Reid (2008) found that the PHQ-9 was reliable (Chronbach’s  $\alpha$  at baseline 0.83); demonstrated convergent and discriminant validity, robustness of factor structure, and responsiveness to change.

#### *Qualitative interviews*

The qualitative interview asked participants about their experiences of using Talking Point. It covered: what they found useful and less useful about Talking Point; how they liked to make use of Talking Point, for example, whether they preferred to write posts or read other peoples’; whether they felt that Talking Point had made a difference to them and their role as a carer. The interview schedule (Appendix 12) was developed with reference to some previous literature on peer support, as well as through discussion with the Talking Point Manager and the Alzheimer’s Society Head of Quality and Service Evaluation. The Talking Point Manager and volunteer moderators provided feedback during the development of the

interview schedule. Seven interviews were conducted over the telephone and one was face-to-face. Interviews lasted for between 35 and 50 minutes.

### *Researcher perspective*

It is recommended that the researcher's perspective is disclosed in order to contribute to the credibility of qualitative research (Barker & Pistrang, 2005; Elliott, Fischer & Rennie, 1999). I am a white, middle class female in my twenties and I conducted this research as part of my doctoral training in clinical psychology. I have no direct experience of caring for a friend or family member with dementia, but have seen the impact of the caring role upon people that I know. Through this, I am aware of the challenges and stress that this role can bring, and this has contributed to my belief that appropriate support to reduce distress in this group of people is important.

### **Analysis**

Paired sample t-tests were used to analyse baseline to 12 weeks changes in anxiety, depression and quality of relationship for all participants who completed the survey at 12 weeks. Non-parametric correlations were conducted to examine the relationship between forum usage level and changes in outcome.

Interviews were transcribed verbatim, with all identifiable data removed in order to preserve anonymity. Semi-structured interviews were analysed using thematic analysis as outlined in Braun and Clarke (2006), using an inductive, data-driven approach. Interview transcripts were repeatedly reviewed in order to become familiar with the data and to ensure that information was represented accurately. During this process, an initial list of ideas was generated. These were grouped into codes and then brought together into meaningful themes (see Appendix 13 for a sample sheet of coded interview transcript). These themes were then checked against initial codes and the overall data set. In some instances, themes were then amended,

and themes were organised into overarching domains. Credibility checks (Elliott et al., 1999; Stiles, 1993) involved another researcher examining sections of analysed interview transcripts and providing feedback on codes, themes and domains.

Respondent validation was used as a further credibility check. In order to gain feedback from interview participants, each participant was emailed a summary of the themes generated from their interview and asked to complete and return a feedback form (Appendix 14). Seven of the eight interview participants responded to this, either by completing the form or simply by replying to the email, and said they felt that the list of themes was a good summary of the interview.

## **Results**

### **Quantitative analysis**

There was no missing data for the three main outcome measures at baseline, nor for any participants who completed the survey at 12 weeks (the online survey did not allow respondents to continue with the survey if data was missing). Three participants' usage data was internally inconsistent. For example, they might have reported that they had visited the forum 10 times, but that they had spent 0 minutes on the forum. Where this occurred, all usage data for that participant was coded as missing. Two additional participants gave unclear answers regarding the amount of time spent on the forum, and this was also coded as missing.

The distribution of PHQ-9 scores was positively skewed, so a square root transformation was carried out. This did not, however, affect the significance of any results. For significance testing, the transformed scores are used, and where means and standard deviations are reported, the untransformed data is used.

*Differences at baseline between those who completed the survey at 12 weeks and those who did not*

Table 3 shows the differences in baseline PHQ-9, GAD-7 and SQCGR scores between those who completed the survey at 12 weeks and those who did not. There were no differences between the two groups. Of those who did not complete the survey at 12 weeks, 25 (43%) participants were receiving no informal support and 30 (52%) were receiving no formal support. Of those who completed the survey at 12 weeks, 26 (43%) had said that they were receiving no informal support, and 25 (41%) were receiving no formal support.

Table 3: Baseline scores for those who completed the survey at 12 weeks and those who did not

	<i>M (SD)</i>		<i>t (df)</i>	<i>p</i>	<i>d</i>
	Non-completers	Completers			
PHQ-9 <sup>a</sup>	9.78 (7.35)	9.75 (6.65)	.39 (117)	.694	0.07
GAD-7	10.38 (6.65)	10.38 (6.44)	.002 (117)	.999	0.00
SQCGR	46.69 (10.08)	48.61 (9.20)	-1.09 (117)	.280	-0.12

<sup>a</sup>Note that t-tests were performed on the square root transformed PHQ-9 scores

*Usage data*

Of the 58 participants whose forum usage data was available, 17 (29%) reported that they had not visited the forum at all over the 12 week study period. There were no differences in these two groups' baseline scores on any of the three measures (Table 4).

Table 4: Comparison of baseline scores between those who reported that they had used Talking Point and those who reported that they had not

	<i>M (SD)</i>		<i>t (df)</i>	<i>p</i>	<i>d</i>
	Users	Non-users			
PHQ-9 <sup>a</sup>	9.98 (6.51)	8.88 (6.78)	.52 (56)	.609	0.15
GAD-7	9.83 (6.14)	10.71 (6.15)	-.47 (56)	.641	0.14
SCQCR	49.00 (9.04)	46.88 (9.86)	.79 (56)	.432	0.23

<sup>a</sup>Note that t-tests were performed on the square root transformed PHQ-9 scores

Overall, usage was low; 44 (76%) participants reported visiting the forum fewer than 12 times over the 12 week study period. Of those participants who visited the forum, 18 (44%) never replied to any posts, and 20 (49%) never started their own new thread or post. Table 5 shows participants' reported usage data over the 12 week study period.

Table 5: Reported usage levels over the 12 week study period

	Range	<i>M</i>	<i>SD</i>
Number of forum visits	0-200	17.43	37.14
Number of minutes spent on forum	0-3000	373.57	589.86
Number of messages/posts written as a reply to someone else	0-400	14.53	54.76
Number of new threads/posts started	0-50	2.67	8.04

#### *Pre and post outcome comparisons*

Of those who completed the survey at 12 weeks, 16 (26%) of them had a “poor” relationship with the person with dementia at baseline (scores of 42 or less on the SCQCR); 19 (31%) fell in the “severe” range for anxiety on the GAD-7 at baseline (scores of 15 or more) and six (10%) fell in the “severe” range for depression on the PHQ-9 at baseline (scores of 20 or more).

There was an increase in SQCGR scores from baseline to 12 weeks, suggesting an improved relationship quality with the person with dementia, but no change in PHQ-9 or GAD-7 scores (Table 6).

Table 6: Pre and post outcome measure scores for all participants who completed the survey at 12 weeks

	<i>M (SD)</i>		<i>t (df)</i>	<i>p</i>	<i>d</i>
	Baseline	Time 2			
PHQ-9 <sup>a</sup>	9.75 (6.65)	9.23 (6.82)	0.75 (60)	.457	0.19
GAD-7	10.38 (6.44)	9.72 (6.63)	0.95 (60)	.348	0.24
SQCGR	48.61 (9.20)	51.36 (9.87)	-3.04 (60)	0.003	-0.78

<sup>a</sup>Note that t-tests were performed on the square root transformed PHQ-9 scores

### *Individual change*

Table 7 shows reliable change analysis at the level of individual participants (Evans, Margison, Barkham, 1998). Alpha levels for the three measures were obtained from: Martin et al., 2006 (PHQ-9); Löwe et al., 2008 (GAD-7); Spruytte et al., 2002 (SQCRC).

Table 7: Reliable change analysis

Measure	Reliably improved	No change	Reliably deteriorated
PHQ-9	9 (15%)	48 (79%)	4 (7%)
GAD-7	11 (18%)	41 (67%)	9 (15%)
SQCGR	5 (8%)	55 (90%)	1 (2%)

### *Usage level and outcome*

In order to investigate the hypothesis that users' outcomes would be related to their level of forum usage, non-parametric correlational analyses investigating

outcome data and usage data were conducted with data from participants who said that they had visited the forum at least once over the 12 week study period. Only one of these correlational tests was significant, and given the number of tests that were conducted, the chance of this result being a Type I error is high. Thus, usage level was not correlated with outcome.

### **Qualitative analysis**

Thematic analysis of the eight semi-structured interviews resulted in 18 themes across three domains (Table 8). Each domain and theme is discussed with illustrative interview quotes.

#### *Domain 1: Social similarity*

All interview participants discussed in detail the fact that Talking Point is a forum for people who are in the same situation, caring for someone with dementia. For the most part, this was considered to be a great benefit, although it was also noted by some that it brought disadvantages as well.

##### *1.1 I am not the only one going through this*

Six participants spoke about connecting with other carers of people with dementia on Talking Point, and their relief and comfort in knowing that they were not the only person going through the experience of caring.

*“Every time I realise “that’s me, that’s me! I’m going through that, that’s me!” I can relate to so much of what’s on there” [P1]*

##### *1.2 Reduced isolation and loneliness*

Seven participants noted that being able to use Talking Point reduced their sense of isolation or loneliness. For some, this was in the context of becoming more isolated as a result of their family member having dementia.

Table 8: Thematic analysis

Domain		Theme	Prevalence*
1. Social similarity	1.1	I am not the only one going through this	Typical
	1.2	Reduced isolation and loneliness	General
	1.3	Normalising	Typical
	1.4	Other users have experience and are therefore understanding	Typical
	1.5	Being able to share and let off steam	Typical
	1.6	Other users are worse off than I am	Typical
	1.7	Not necessarily needing to post to benefit	General
	1.8	Being able to give advice and support to other users	General
2. Unique aspects	2.1	I can ask questions and get the support that I might not be able to get, or might not want to get, elsewhere	Typical
	2.2	I can get information and advice that I would not know where else to get	Rare
	2.3	Control	Typical
	2.4	Anonymity	Typical
	2.5	Immediate access and responses	Variant
	2.6	No time restrictions	Variant
	2.7	Geography is unimportant	Variant
3. Learning outcomes	3.1	Practical learning and information	General
	3.2	Learning how the dementia might progress and what to expect	Typical
	3.3	Developing a better understanding of the person with dementia, and consequently becoming a better carer	General

\*General = theme applies to all or all but one of the participants (7-8); typical = theme applies to more than half of the participants (5-6); variant = theme applies to up to half of participants (3-4); rare = theme applies to one or two participants (1-2).

*“All of a sudden, I’m in the flat on my own. And I have nobody to talk to, and you go a little bit odd at times. I don’t drink and I don’t smoke, so the only thing I’ve got now, really, is Talking Point” [P5]*

For most participants, this sense of feeling less isolated and alone occurred within the context of having other support available, but still feeling alone before joining Talking Point.

*“Before my son introduced me to that [Talking Point] I felt that I was on my own, even though like I said I have fantastic support from the help service and family and everything, it still, I still felt alone” [P1]*

### *1.3 Normalising*

Six participants noted that because other Talking Point users were in a similar situation to them, they were able to go onto Talking Point and realise that what they were experiencing was normal.

*“I’m feeling like I want my dad to die, because I don’t want to see him go through this, and he’d be happier. And then you feel full of guilt, but you go on [to Talking Point], and you’re not the only one feeling that, or you’re not the only one that has felt that. And it makes you feel OK, normal.” [P3]*

*“And I put that on Talking Point. And I had six answers back saying that, yes we’ve all been through that. It does happen. And that made me feel better.” [P4]*

### *1.4 Other users have experience and are therefore understanding*

Six participants reflected that because other Talking Point users know what caring for a friend or family member with dementia is like, they understand your struggles and can support you.

*“I was just so emotional with it all. And unfortunately I went online. Just to let it out, you know. This is the thing you see, this is the only forum where you can do this kind of thing, and people don’t judge you. They come in and try to help. And they make allowances, because they’ve been there. And that is the great strength of it. Everybody on Talking Point has hands on experience of dealing with dementia. And they make allowances for you, as they did for me.” [P5]*

This experience and understanding also means that large amounts of background information do not need to be explained to others on Talking Point.

*“There are things you don’t have to go into massive detail about, because it’s a given” [P8]*

#### *1.5 Being able to share and let off steam*

Five participants reflected on the value of Talking Point in being able to share their experiences with others. Several described this as a cathartic process.

*“I think being able to share your experiences is a great help” [P6]*

*“It makes you feel unbelievably relieved, because I know that I can share something with this person and they can share with me” [P8]*

*“If nothing else, it’s purely somewhere to let off steam” [P4]*

#### *1.6 Other users are worse off than I am*

Several participants commented on the fact that other users of Talking Point were in a much worse situation than they were. Three participants reflected that knowing this, and reading these people’s stories, made them feel more positive about their own caring situation.

*“My goodness, some people are dealing with some incredibly difficult situations. And how on earth do they cope? And you know, those*

*situations, my goodness, the situation we've got at the moment is not that difficult, we ought to be able to work around it.” [P7]*

However, for three interviewees, the experience of reading other users' posts had at times been a very distressing experience for them.

*“If I'm online and I'm reading other people's posts and it's quite distressing, you know, it's quite easy to get distressed by it. So there are times when I just don't go on it because I think, oh, it's too painful, really, for me” [P2]*

#### *1.7 Not necessarily needing to post to benefit*

Seven participants noted that because everyone on Talking Point was a carer of someone with dementia, they could both feel supported and learn a large amount by simply reading other posts.

*“I do like to read the other posts... Because I feel the more information I have, the better carer I will be” [P8]*

*“I think it's more useful for me to read other people's experiences” [P6]*

#### *1.8 Being able to give advice and support to others*

Seven participants noted that they had been able to give advice and support to other users of Talking Point. For some there was pleasure derived from being able to give something back.

*“It's nice to be giving something back for the information that you're getting. Or being able to support people as the support you receive” [P3].*

Others noted that they felt good being able to help others, and it also showed them that they did in fact have valuable knowledge to pass on.

*“It’s helpful in that you think, well, at least you know slightly more than someone else... It gives you a little bit of a boost to know that you can help somebody” [P6]*

#### *Domain 2: Unique aspects*

All eight participants made comments comparing Talking Point to existing or alternative sources of information and support. Sometimes an explicit link was made between Talking Point and other forms of support, but more commonly participants spoke simply in terms of the advantages that they felt Talking Point offered to them.

*2.1 I can ask questions and get the support that I might not be able to get, or might not want to get, elsewhere*

Six participants commented that Talking Point provided them with a place to get information and support that they may not be able to get, or may not want to get elsewhere. One participant did not believe that the type of information she could get on Talking Point would be available in more conventional contexts.

*“It’s not the kind of thing you would read in a leaflet that you pick up anywhere. I’m assuming. I don’t know. It’s not the kind of thing I assumed I would read in leaflets.” [P6]*

Others commented that they might not want to seek support or answers to questions through their pre-existing sources of information or support.

*“Me personally, I don’t want to go sit in front of a – what would you go sit in front of? – a doctor, or a whoever. I don’t want to talk that way” [P3]*

*“I don’t really want to go knock on the doctor’s door every five minutes” [P6]*

## 2.2. *I can get information and advice that I would not know where else to get*

Two participants noted that they were not sure where to get the help or advice that they needed, but that Talking Point was able to provide this.

*“I wasn’t aware then of what help was available” [P4]*

*“For someone who is totally ignorant of Alzheimer’s it has answered questions that I don’t know where I would have got the answer from”*

[P6]

## 2.3 *Control*

Five participants reflected that through using Talking Point they had control. This included control over how often to use the forum.

*“I can go for months without bothering with it... I’ll utilise Talking Point when I need to. That maybe sounds a bit selfish, but I think that’s the advantage of it for me” [P2]*

It also included control in terms of not having to see people with dementia, and being able, to a certain extent, to avoid posts that were too upsetting.

*“You’re not seeing what it’s going to be like, you’re not seeing, you’re not hearing what it’s, you read what you want to read”[P3]*

Participants also noted that they had control in terms of only needing to read posts that were of interest or personally relevant.

*“If I look at the posts and it’s not useful, then I don’t read all of the replies and stuff. So I find it’s very easy to navigate to and from the titles to pick up things that might be useful” [P7]*

## 2.4 *Anonymity*

Four participants commented on the benefits associated with the fact that Talking Point is anonymous, including being able to be more open and honest, and

being able to discuss problems that it might be uncomfortable to discuss in a face-to-face context.

*“What I say there, I am opening up my heart to a very large extent and I am opening myself up and being totally honest about my feelings, and in some cases I wouldn’t want other members of my family, for example, to see some of these things... I wouldn’t want them to know exactly how I feel about certain things. Because when you are with other people you never really uncover your true self, do you?” [P5]*

*“It’s something I could put on there [Talking Point], but I didn’t have to talk face-to-face with anyone” [P3]*

Four participants, however, noted that they had seen some posts on Talking Point that they felt were inappropriate or judgemental. This is another possible consequence of Talking Point’s anonymity. One participant described an experience where she had posted about a situation in her family and received replies from other users who *“put something on about how disgusting it was”* [P2]. She and other participants reflected, however, that Talking Point’s volunteer moderators were generally helpful in these situations.

*“I suppose it’s when you’re sat at home thinking, “oh crikey”, you know, someone thinks that’s really awful. And it puts you in a bit of a panic, but I do think the moderators help because they come back with... solutions” [P2]*

### *2.5 Immediate access and responses*

Three participants reflected on the value of being able to access Talking Point whenever a problem or question arose, and the fact that responses were often also immediate.

*“Now if I have something that is worrying me, I know that I have immediately got someone to talk it over with” [P8]*

### *2.6 No time restrictions*

Three participants commented on the fact that Talking Point can be accessed 24 hours a day, and that use of Talking Point is not time limited, as a more conventional form of support would be.

*“I think professional support is generally very time limited. And Talking Point isn't time limited” [P2]*

### *2.7 Geography is unimportant*

Three participants noted that on Talking Point, it does not matter where users are located. One participant lived outside the UK, and one had previously lived outside the UK, and both reflected on the benefits of Talking Point in their situation.

*“Particularly with me being mobile around the world as well as the country, it's offered a support that I wouldn't have had otherwise” [P7]*

## *Domain 3: Learning Outcomes*

All participants identified learning outcomes from using Talking Point, and many reflected that what they had learned on Talking Point had helped them to become better carers.

### *3.1 Practical learning and information*

All eight participants commented that Talking Point had provided them with practical advice and information. This ranged from information about Attendance Allowance, to information about how to deal with people with dementia turning on an empty microwave, to one participant buying her father a cat.

*“Off Talking Point, someone said that animals are really good. So I got him a kitten... It was absolutely brilliant, and I thought “thank God for Talking Point” because when my mum had to go out, he had the kitten to talk to, and the kitten to play with, and the cat even now.”*

[P3]

### *3.2 Learning how the dementia might progress and what to expect*

Five participants noted that Talking Point had provided them with information about how their family member's dementia might progress and what to expect in the future. For some participants, this meant that when certain events did occur, they were more prepared for them and thus less anxious when they did occur.

*“That happened three times in the last few weeks, where [husband] hadn't known where he was. And it has been stressful for him. But had I not known about it, I might have worried more. But having read about it [on Talking Point], I thought, mmm, yes, things do happen”*

[P6]

For others, this information meant that they felt forewarned and therefore forearmed in terms of the next stages of the dementia.

*“When you're reading it, you're thinking “I've got all this to come”, but at the same time, you're planning” [P3]*

One participant expressed sadness that through what she had read on Talking Point, she had started to look for certain behaviours in her husband.

*“I now look for the kind of problems that other people are having, that I am not having... And so that saddens me in a way that I possibly know more and am looking for things, and really I shouldn't be” [P6]*

### *1.3 Developing a better understanding of the person with dementia, and consequently becoming a better carer*

Seven participants reflected that what they had learned on Talking Point had helped them to understand more about dementia and so become better carers.

*“I'm understanding more of what he does” [P1]*

*“I'm more understanding. I don't fly off the handle” [P4]*

*“I don't reason with her any more, I agree, and I can steer the conversation, and I know the kinds of things to say and the kinds of things to stay away from. And I think I'm a much better person for Talking Point. A much better companion for my wife, I know that.”*

[P5]

## **Discussion**

This mixed-methods study evaluated Talking Point, the Alzheimer's Society's online support forum for carers of people with dementia. Changes in the quality of the relationship were examined, and it was found that there was an improvement in the carers' quality of relationship with the care recipient after 12 weeks. The hypotheses that after 12 weeks of forum usage, users' anxiety and depression would decrease, were not supported. It is noteworthy, however, that depression and anxiety levels did not increase. In interviews with users of Talking Point, they reported a

range of benefits from using Talking Point, as well as a small number of less positive experiences.

The quality of relationship with the person with dementia improved after 12 weeks of forum usage. Qualitative results provide some insight into how Talking Point may have improved the carers' relationship with the person with dementia, for example through carers learning more about how to interact with someone with dementia and feeling as though the information that they had gathered helped them to become a better carer. Many participants' forum usage level was low, and it is possible that for some participants, being aware of Talking Point as a resource that was available should they wish to use it, was enough to improve the quality of their relationship with the person that they were caring for. There may also have been another variable involved: it is possible that those who signed up to Talking Point were people who had made the decision to learn and develop as much as possible in their role as a carer, and these individuals were motivated to have a good quality relationship with the person with dementia.

The findings in the literature regarding carers' psychological wellbeing over time are mixed. This complicates interpretation of the finding that anxiety and depression remained relatively stable over the 12 week study period. There is a range of models for how carer wellbeing might progress over time. The wear-and-tear model postulates that carer psychological health deteriorates progressively as the care recipient's functioning decreases; the adaptation model suggests that carer psychological health either increases or stabilises over time as the person with dementia deteriorates; the trait model suggests that because the carer has "stable resources" such as coping strategies, that do not change over time, their mental health remains relatively stable (Pot, 2004). Just as a number of factors have been

shown to affect the level of psychological wellbeing in dementia carers (see, for example, Janevic & Connell, 2001), it seems that the pattern of progression of psychological distress in these carers is also affected by a range of factors. These include intrinsic variables, such as carer gender (Schulz & Williamson, 1991) and more contextual factors such as the relationship between carer and care recipient, for example whether the carer is the care recipient's spouse or their child (Zarit & Whitlatch, 1992). This complicates interpretation of the present findings as these factors varied across the sample.

Overall, the usage level of Talking Point was low amongst participants. It is likely that any potential benefits of the forum would have been greater if usage had been higher. Other research has found an association with online support usage level and outcome. For example, Houston, Cooper and Ford (2002) found that reduction in depression was correlated with usage levels of an online support group for depression. It may be that if usage levels had been higher, a reduction in anxiety and depression may have been found. It is, however, also possible that Talking Point simply does not affect users' levels of depression and anxiety, and that interventions for carers of people with dementia need to be multicomponent in nature to bring about changes in anxiety and depression (Beauchamp, Irvine, Steeley & Johnson, 2005; Pillemer & Sutor, 2002).

With regards to changes at the individual level, for all three measures most participants' scores neither reliably improved nor reliably deteriorated. More participants reliably improved than reliably deteriorated. Given that research suggests that the relationship quality is likely to deteriorate over time (see, for example, Gallagher-Thompson et al., 2001; de Vugt et al., 2003), although this research only covered a 12 week period, this finding is encouraging. Although

research into the trajectories of anxiety and depression is more mixed (Pot, 2004), this is also an encouraging finding in relation to these measures.

Qualitative information provides more detailed insight into carers' experiences of using Talking Point. Mixed-methods studies have been used previously in carer intervention research for similar reasons (for example, Torp, Hanson, Hauge, Ulstein, & Magnusson, 2008). The eight carers interviewed were generally very positive in the way that they spoke about Talking Point. Their reasons for using Talking Point echo findings from previous research, where content analysis has found that the primary functions of such groups are to exchange information, connect to others, and to obtain emotional support (Mo & Coulson, 2012).

For interviewees, the fact that other users of Talking Point were in a similar situation to them had a range of benefits, as well as a few disadvantages. For many carers, the realisation that they were not alone in caring was a benefit for them. Carers of people with dementia frequently report feelings of isolation and inadequate social support (Stoltz et al., 2004), but interview participants reported that using Talking Point reduced their sense of isolation and loneliness. They reported that being able to share with others and “let off steam” was another benefit. They also reported feeling more normal when they heard that other users had experienced events or emotions similar to those that they had. Goffman’s (1963, p31) work in relation to stigma can perhaps be applied in this context as well: “he will find that there are sympathetic others who are ready to adopt his standpoint in the world and to share with him the feeling that he is human and ‘essentially’ normal in spite of appearances and in spite of his own self-doubts”. A number of Yalom’s (1985) therapeutic factors from groups were reported by interviewees, including: universality, altruism, guidance, imparting information and catharsis.

Interview participants reflected that other users of Talking Point had experience of dementia, and so were understanding of the struggles that they faced. Coreil, Wilke and Pintado (2004) and Gray, Fitch, David and Phillips (1997) similarly found that relationships forged in support groups were founded on a unique understanding of the experience of the illness, which cannot be replicated in those who have not experienced the illness.

Social Comparison Theory, initially proposed by Festinger (1954) suggests that we have a drive for accurate self-evaluations, which we base on comparison of others. It seems that this process is at work on Talking Point. Several interviewees noted that seeing that others were worse off helped them to feel better about their own situation. No interviewee mentioned comparing themselves to individuals who were in a better situation than they were. Benefits of downward comparison have been seen in other studies of online support groups for health conditions (for example, Locock & Brown, 2010; van Uden-Kraan et al., 2008). However, for several participants, reading the stories of other users who were in worse situations was a very distressing experience.

Interviewees reportedly derived benefit not only from receiving support and information, but also from being able to help others. The “helper therapy principle” (Riessman, 1997) has been discussed extensively in relation to peer support. Put simply, the principle is that people help themselves by helping others. Roberts et al. (1999) evaluated a mutual support group for individuals with serious mental health problems, and found that giving help to others in the group predicted improvements in psychosocial adjustment. A number of mechanisms have been suggested for why helping others is beneficial, including that providing help can increase feelings of competence, equality, social usefulness, independence and social value, as well as

allowing individuals to view themselves as having strengths as well as needs (Roberts et al., 1999). This sort of benefit would not be available in a one-to-one professional support context and is perhaps therefore a benefit that is unique to peer support.

Using thematic analysis of forum posts, Barak and Dolev-Cohen (2006) found that, on an online support forum for suicidal and severely distressed adolescents, the higher the number of posted messages and replies, the lower the level of distress manifested by users in the following months. In the present study, interviewees reported feeling that they benefitted from using Talking Point without actually needing to post, although this reported benefit may not necessarily have been a reduction in distress. A study by Malik and Coulson (2011) found that both “lurkers” and “posters” on an online infertility support group reported gaining a range of benefits that were unique to online support, lending weight to the argument that reading messages may be as beneficial as interacting with the group.

Interview participants mentioned features and benefits of Talking Point that could be considered to be in contrast to other, more traditional services. A number of interviewees reflected that the type of information and support available on Talking Point was either not available to them elsewhere, or that they would not wish to obtain it elsewhere. Gray et al.’s (1997) study of peer support for women with breast cancer similarly found that some of the information gained from the peer support group would and should not be expected to be gained from healthcare professionals. It may therefore be that Talking Point either works as a useful complement to other services, and/or that it offers a service to people who may not access other services, and so fills a unique niche. A number of interviewees were not the main carer of the

person with dementia, and it may be that more traditional services are therefore not available to them as they would be to primary carers.

Talking Point's anonymity provided a number of interviewees with the freedom to say more than they felt that they would be able to with people that they knew, or in a face-to-face context. This has been referred to as the online disinhibition effect (Suler, 2004), and brings with it a range of advantages and disadvantages. It may have been that those users who were able to be more open about their feelings were consequently able to receive more emotional support from their peers online than from friends and family. However, several interview participants also described posts on Talking Point that they considered to be judgemental or inappropriate. It is important that online support forums are moderated so that the more toxic online disinhibition effects (Suler, 2004) can be controlled as much as possible. Talking Point has a number of volunteer moderators who several interview participants felt were a great help in such situations. In addition, some participants commented on the fact that Talking Point provided them with the control to only read posts that they wanted to. This most likely goes some way to minimise the distress of reading other posts that are either considered to be judgemental or that users find to be upsetting.

All participants interviewed reflected that they had learned a range of things from Talking Point, and this was often in the form of information that might not be available from more traditional information sources, or individuals would not wish to ask professionals about. Again, this highlights that online peer support may fill a unique niche for carers of people with dementia.

A number of participants noted that reading other people's posts on Talking Point helped them to learn more about how the dementia might progress and so be

better prepared for events that might occur in the future. Participants also spoke about finding some posts too distressing and not wanting to read them. This suggests something of a tension between wanting to read posts to gain information about dementia, but also an avoidance of some of this information. For carers of people with dementia, managing uncertainty about the progression of the dementia is not necessarily a straightforward task. With a disease that involves worsening of symptoms over time, more information and therefore less uncertainty about the future can provide relief, but it can also cause distress, and more information is not always positive. This finding has also been found in a study of support groups for people with Motor Neurone Disease, another disease where there is no prospect of recovery, and their carers (Locock & Brown, 2010).

Participants described not only gaining practical information from using Talking Point, but also learning more about how to interact with someone with dementia, and so becoming a better carer or companion. It is noteworthy that the outcomes from using Talking Point, as reported by interview participants, not only benefited the carers but also may perhaps have benefited the person with dementia as well, in that the care they received may well have improved.

### **Limitations**

One surprising finding from the research was that forum usage levels were generally very low. A large minority of participants said that they did not visit the forum at all over the research period, and many more said that they visited only a handful of times. Having said that, usage data was also based on retrospective self-report, which brings into question its accuracy. One might anticipate that if the forum were to be of benefit to carers, higher levels of engagement with it would result in greater benefits. However, this study perhaps provides a realistic picture of carers'

level of forum usage. Indeed, as a number of interview participants noted, one of Talking Point's benefits for them was that they could log on as little or as often as they wished.

Although the psychometric properties of the GAD-7 and the PHQ-9 have been extensively investigated, the psychometric properties of the SQCRC are somewhat limited, which means that the findings in relation to this measure must be interpreted somewhat tentatively.

It would have been ideal to have a longer time period between baseline and the second survey to get a clearer picture of the longer term effects of Talking Point. In addition, interviews were conducted with participants who reported using Talking Point more than six times during the 12 week study period. The experiences of those who used the forum less, or disengaged from using the forum, may well have been different to those of interview participants.

Although the fact that participants were receiving various levels of additional formal and informal support in their roles as carers is a realistic picture of the people who use Talking Point, it does further complicate and limit the scope of conclusions that can be made about the specific role of Talking Point. Participants were carers in a range of different situations and it was beyond the scope of this study to consider all of these variables, although it is likely that many of these, such as number of hours spent caring and relationship with the person with dementia (e.g. spouse or parent), could have affected their engagement with, and the benefits that they derived from, Talking Point.

Only around 3% of possible participants took part in the research. These sampling issues inevitably limit the extent of conclusions that can be made, and the extent to which quantitative findings from the present research can be generalised.

The lack of a control group in the present research also means that findings cannot necessarily be attributed to forum usage.

One reason for the discrepancy between qualitative and quantitative findings is that all eight interview participants reflected positively on the practical benefits of Talking Point and the information and advice that they had gained, while all three outcome measures used in the research investigated psychological and interpersonal factors. While the receipt of useful practical advice may have had an impact on these outcomes, it may be that for some users, gaining practical advice was the only benefit of visiting Talking Point, but that this was of great importance to them. Some interview participants said that they did not want or require emotional support and that they used Talking Point for practical advice. This raises questions about why people visit Talking Point and what they are seeking to gain. It highlights that outcome measures must both capture what is important to carers (Magnusson, Hanson & Nolan, 2005; Schulz et al., 2002), as well as the aims of the intervention.

### **Implications**

Qualitative data suggests that some of the benefits of using Talking Point are unique to peer support or group therapy, such as feeling as if one is not alone and feeling that others understand because they have experience; and some of the benefits are unique to online support, such as being able to be more honest about one's struggles in an anonymous online environment. Clinicians may therefore wish to direct carers to such online peer support forums in order for carers to experience these unique benefits. In an economic climate where costs are being cut and services are often being reduced, online peer support is likely to become more prevalent and may well be the only support that some carers receive. It is therefore important that

this area continues to be researched so that carers can derive maximum benefit from online peer support forums.

Future research would benefit from investigating in greater detail what outcomes are important to carers and specifically consider these outcomes in the evaluation of online carer support interventions. In addition, more research needs to be done into whether different types of carers (e.g. according to gender and ethnicity) derive different types or levels of benefit from online peer support forums, since evidence from previous research (e.g. Eisdorfer et al., 2003; Mahoney et al., 2003) suggests that interventions do not affect carers uniformly. In order that carers receive the best support possible, it would also be worthwhile investigating whether there are certain types of support that work well when offered in conjunction with online peer support and vice versa. Research suggests that interventions for carers of people with dementia are often most effective when they are multicomponent in nature (Beauchamp et al., 2005; Pillemer & Sutor, 2002), although inevitably this makes evaluation and attribution of any observed effects more complex (Schulz et al., 2002).

## **Conclusions**

This research found that after 12 weeks of forum usage, users' quality of relationship with the person with dementia improved. It did not find a reduction in anxiety or depression after 12 weeks of forum usage. Qualitative data from interviews with users of Talking Point highlighted a number of positive experiences and benefits that users felt that they had gained from using the forum, including emotional support, practical advice and information, as well as becoming a more effective carer of the person with dementia. Many of these reported benefits and experiences are unique to online peer support. Further research into online peer

support for carers of people with dementia is needed in order that such support can be designed so that carers derive maximum benefit.

## References

- Alzheimer's Society (2011). *Alzheimer's Society: Statistics*. Retrieved 21 July 2011 from:[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=341](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=341)
- Barak, A. & Dolev-Cohen, M. (2006). Does activity level in online support groups for distressed adolescents determine emotional relief. *Counselling and Psychotherapy Research, 6*, 186-190.
- Barker, C. & Pistrang, N. (2002). Psychotherapy and social support: Integrating research on psychological helping. *Clinical Psychology Review, 22*, 361-379.
- Barker, C. & Pistrang, N. (2005). Quality criteria under methodological pluralism: Implications for conducting and evaluating research. *American Journal of Community Psychology, 35*, 3, 201-212.
- Beauchamp, N., Irvine, A.B., Seeley, J. & Johnson, B. (2005). Worksite-based internet multimedia program for family caregivers of persons with dementia. *The Gerontologist, 45*,6, 793-801.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101.
- Brennan, P.F., Moore, S.M. & Smyth, K.A. (1995). The effects of a special computer network on caregivers of persons with Alzheimer's Disease. *Nursing Research, 44*, 3, 166-172.
- Cameron, I.M., Crawford, J.R., Lawton, K. & Reid, I.C. (2008). Psychometric comparison of PHQ-9 and HADS for measuring depression severity in primary care. *The British Journal of General Practice, 58*,546, 32-36.
- Cohen, J. (1992). A power primer. *Psychological Bulletin, 112*, 1, 155-159.

- Coreil, J., Wilke, J. & Pintado, I. (2004). Cultural models of illness and recovery in breast cancer support groups. *Qualitative Health Research, 14*, 7, 905-923.
- Davison, K.P., Pennebaker, J.P. & Dickerson, S.S. (2000). Who talks? The social psychology of illness support groups. *American Psychologist, 55*, 2, 205-217.
- De Vugt, M.E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., Winkens, I., Jolles, J. & Verhey, F.R.J. (2003). Behavioural disturbances in dementia patients and quality of the marital relationship. *International Journal of Geriatric Psychiatry, 18*, 149-154.
- Eisdorfer, C., Czaja, S.J., Loewenstein, D.A., Rubert, M.P., Argüelles, S., Mitrani, V.B. & Szapocznik, J. (2003). The effect of a family therapy and technology-based intervention on caregiver depression. *The Gerontologist, 43*, 4, 521-531.
- Elliott, R., Fischer, C.T. & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38*, 215-229.
- Evans, C., Margison, F. & Barkham, M. (1998). The contribution of reliable and clinically significant change methods to evidence-based mental health. *Evidence Based Mental Health, 1*, 70-72.
- Eysenbach, G., Powell, J., Englesakis, M., Rizo, C. and Stern, A. (2004). Health related virtual communities and electronic support groups: Systematic review of the effects of online peer to peer interactions. *British Medical Journal, 328*.
- Faul, F., Erdfelder, E., Buchner, A., & Lang, A.G. (2009). Statistical power analyses using G\*Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods, 41*, 1149-1160.

- Festinger, L. (1954). A theory of social comparison processes. *Human Relations*, 7, 117-140.
- Gallagher-Thompson, D., Dal Canto, P.G., Jacob, T. & Thompson, L.W. (2001). A comparison of marital interaction patterns between couples in which the husband does or does not have Alzheimer's Disease. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 56B,3, 140-150.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New Jersey: Prentice-Hall Inc.
- Gray, R., Fitch, M., Davis, C. & Phillips, C. (1997). A qualitative study of breast cancer self-help groups. *Psycho-oncology*, 6, 4, 279-289.
- Houston, T. K., Cooper, L. A., & Ford, D. E. (2002). Internet support groups for depression: A 1-year prospective cohort study. *American Journal of Psychiatry*, 159, 2062-2068.
- Janevic, M.R. & Connell, C.M. (2001). Racial, ethnic and cultural differences in the dementia caregiving experience: Recent findings. *The Gerontologist*, 41, 3, 334-347.
- Kendall, J. (1992). Promoting wellness in HIV-support groups. *The Journal of the Association of Nurses in AIDS Care*, 3,1, 28-38.
- Kroenke, K., Spitzer, R.L. & Williams, J.B.W. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine*, 16,9, 606-613.
- Kroenke, K., Spitzer, R.L., Williams, J.B.W., Monahan, P.O. & Löwe, B. (2007). Anxiety disorders in primary care: Prevalence, impairment, comorbidity and detection. *Annals of Internal Medicine*, 146, 317-325.

- Locock, L. & Brown, J.B. (2010). 'All in the same boat'? Patient and carer attitudes to peer support and social comparison in Motor Neurone Disease (MND). *Social Science & Medicine*, 71, 1498-1505.
- Löwe, B., Decher, O., Müller, S., Brähler, E., Schellberg, D., Herzog, W. & Herzberg, P.Y. (2008). Validation and standardization of the generalized anxiety disorder screener (GAD-7) in the general population. *Medical Care*, 46, 3, 266-274.
- Magnusson, L., Hanson, E. & Nolan, M. (2005). The impact of information and communication technology on family carers of older people and professionals in Sweden. *Aging and Society*, 25, 693-713.
- Mahoney, D.F., Tarlow, B.J. & Jones, B.J. (2003). Effects of an automated telephone support system on caregiver burden and anxiety: Findings from the REACH for TLC intervention study. *The Gerontologist*, 43,4, 556-567.
- Malik, S. H. & Coulson, N. S. (2011). A comparison of lurkers and posters within infertility online support groups. *Computers Informatics Nursing*, 29, 564-573.
- Martin, A., Rief, W., Klaiberg, A. & Braehler, E. (2006). Validity of the Brief Patient Health Questionnaire Mood Scale (PHQ-9) in the general population. *General Hospital Psychiatry*, 28, 71-77.
- Mo, P. K. H. & Coulson, N. S. (2012). Developing a model for online support group use, empowering processes and psychosocial outcomes for individuals living with HIV/AIDS. *Psychology & Health*, 27, 445-459.
- Pillemer, K. & Suitor, J.J. (2002). Peer support for Alzheimer's caregivers: Is it enough to make a difference?. *Research on Aging*, 24, 171-192.

- Pistrang, N., Barker, C. & Humphreys, K. (2008). Mutual help groups for mental health problems: A review of effectiveness studies. *American Journal of Community Psychology*, 42,1, 110-121.
- Pot, A.M. (2004). The care-giving stress process. In G.M.M. Jones & B.M.L. Miesen (Eds) *Care-giving in dementia: Research and applications* (3<sup>rd</sup> ed.) Hove: Brunner-Routledge.
- Powell, J., Chiu, T., & Eysenbach, G. (2008). A systematic review of networked technologies supporting carers of people with dementia. *Journal of Telemedicine and Telecare*, 14,3, 154-156.
- Riessman, F. (1997). Ten self-help principles. *Social Policy*, 28, 6-19.
- Roberts, L.J., Salem, D.A., Rappaport, J., Toro, P.A., Luke, D.A. & Seidman, E. (1999). Giving and receiving help: Interpersonal transactions in mutual-help meetings and psychosocial adjustment of members. *American Journal of Community Psychology*, 27, 841-868.
- Schulz, R. & Beach, S.R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *The Journal of the American Medical Association*, 282, 23, 2215-2219.
- Schulz, R. & Martire, L.M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry*, 12,3, 240-249.
- Schulz, R., O'Brien, A.T., Bookwala, J. & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates and causes. *The Gerontologist*, 35,6, 771-791.
- Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L.M., Belle, S.H., Burgio, L., Gitlin, L., Coon, D., Burns, R., Gallagher-Thompson, D. &

- Stevens, A. (2002). Dementia caregiver intervention research: In search of clinical significance. *Gerontologist*, 42, 5, 589-602.
- Schulz, R. & Williamson, G.M. (1991). A 2-year longitudinal study of depression among Alzheimer's caregivers. *Psychology and Aging*, 6, 569-578.
- Solomon, M., Pistrang, N. & Barker, C. (2001). The benefits of mutual support groups for parents of children with disabilities. *American Journal of Community Psychology*, 29,1, 113-132.
- Spitzer, R.L., Kroenke, K., Williams, J.B.W. & Löwe, B. (2006). A brief measure for assessing generalised anxiety disorder: The GAD-7. *Archives of Internal Medicine*, 166, 1092-1097.
- Spruytte, N., Van Audenhove, C., Lammertyn, F. & Storms, G. (2002). The quality of the caregiving relationship in informal care for older adults with dementia and chronic psychiatric patients. *Psychology and Psychotherapy: Theory and Practice*, 75, 295-311.
- Spruytte, N., Van Audenhove, C., & Lammertyn, F. (2000). The scale for the quality of the current relationship in caregiving. Internal Report. LUCAS-KULeuven: Leuven.
- Stiles, W.B. (1993). Quality control in qualitative research. *Clinical Psychology Review*, 13, 593-618.
- Stoltz, P., Udén, G. & Willman, A. (2004). Support for family carers who care for an elderly person at home – a systematic literature review. *Scandinavian Journal of Caring Sciences*, 18,2, 111-119.
- Suler, J. R. (2004). The online disinhibition effect. *CyberPsychology and Behavior*, 7, 321–326.

- Taylor, S.E., Falke, R.L., Shoptaw, S.J. & Lichtman, R.R. (1986). Social support, support groups, and the cancer patient. *Journal of Consulting and Clinical Psychology, 54*, 5, 608-615.
- Torp, S., Hanson, E., Hauge, S., Ulstein, I. & Magnusson, L. (2008). A pilot study of how information and communication technology may contribute to health promotion among elderly spousal carers in Norway. *Health and Social Care in the Community, 16*, 1, 75-85.
- Van Uden-Kraan, C.F., Drossaert, C.H.C., Taal, E., Shaw, B.R., Seydel, E.R. & van de Laar, M.A.F.J. (2008). Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. *Qualitative Health Research, 18*, 405-417.
- Vitaliano, P.P., Young, H.M., Russo, J., Romano, J. & Magana-Amato, A. (1993). Does expressed emotion in spouses predict subsequent problems among care recipients with Alzheimer's disease?. *The Journals of Gerontology, 48*, 202-209.
- White, M.H. & Dorman, S.M. (2000). Online support for caregivers: Analysis of an Internet Alzheimer mailgroup, *Computers in Nursing, 18*, 4, 168-179.
- White, M. & Dorman, S.M. (2001). Receiving social support online: Implications for health education. *Health Education Research, 16*, 6, 693-707.
- Yalom, I.D. (1985). *The theory and practice of group psychotherapy* (3<sup>rd</sup> ed.). New York: Basic Books.
- Zarit, S.H. & Whitlatch, C.J. (1992). Institutional placement: phases of the transition. *The Gerontologist, 32*, 665-672.

## **Part 3: Critical Appraisal**

## **Introduction**

This critical appraisal reflects on some of the issues that arose from the evaluation of Talking Point. It considers: the evaluation of interventions for carers of people with dementia; the challenges of conducting research in a non-face-to-face context; the interview process; the extent of conclusions that can be drawn from the research and; future research.

### **Evaluation of interventions for carers of people with dementia**

An issue raised by the present research, which is echoed in a number of other research studies and reviews, is that of measurement of outcome from interventions for carers of people with dementia (for example, Schulz et al., 2002). The wide range of outcome measures used across studies makes direct comparison of the effectiveness of interventions difficult, and also raises questions about why certain outcome measures are used. Aims of these carer interventions are not always clearly defined, which can bring into question why particular outcome measures were selected over other possible areas to investigate.

On reflection, I wonder whether this ambiguity is something that I was guilty of perpetuating in the present research. The measures I selected made sense conceptually, in that research shows that carers are at risk of depression and anxiety (Schulz & Martire, 2004) and that high levels of expressed emotion are predictive of increased negative behaviours in the person with dementia over time (Vitaliano, Young, Russo, Romano & Magana-Amato, 1993), and it would therefore make sense to investigate whether a carer intervention improved these factors. However, carers are also at risk of other problems, such as high levels of carer burden (Torti, Gwyther, Shelby, Friedman, & Schulman, 2004), and the negative effects of caring on social, family and professional life (Schulz, O'Brien, Bookwala & Fleissner,

1995), and I did not investigate these areas. Inevitably, of course, in such a complex situation, one cannot measure every possible area, and the desire to collect a large number of outcome measures must be tempered by the knowledge that participants will be put off by lengthy surveys. However, I do not feel that I chose these areas of outcome based on any explicit aims of Talking Point.

The Talking Point users who were interviewed all told me about their practical learning and improvements in their skills as a carer resulting from using the forum. Overall, they were positive about Talking Point and the benefits that they felt they derived from it. However, none mentioned feeling less depressed or anxious as a result of using Talking Point. It may well be that their reasons for, and benefits of, accessing Talking Point were at odds with the outcomes that I chose to measure. Qualitative results suggest that the forum is important for a range of other reasons, such as learning about how to interact with someone with dementia and feeling that one is not alone as a carer, and that such benefits might not be available from other sources. This highlights the importance of qualitative research in understanding more about what carers want from interventions and what they perceive the benefits to be.

Qualitative research with carers may help to inform which outcome measures are used in future measurement of the effectiveness of carer interventions, looking at outcomes that are meaningful to carers (Magnusson, Hanson & Nolan, 2005; Schulz et al., 2002), although many of the benefits reported in the present interviews may be less tangible and more difficult to conceptualise in a formal outcome measure. This is particularly problematic in an environment where benefits of interventions often need to be proved quantitatively in order to secure funding. This is further complicated by the fact that one of Talking Point's advantages may be that different carers use the forum for different reasons, and derive different benefits from it. For

example, some may make use of the emotional support, while others appreciate the practical advice and support. Qualitative data certainly contributes to the development of theory about online peer support, however. This may well be why much research into this new but growing area is currently qualitative.

In addition to the aims of interventions, it is also pertinent to consider for whom the intervention is intended to be effective. Carer interventions may benefit the carer, the person with dementia, and there might also be wider cost saving public health benefits, such as reduced institutionalisation of people with dementia. Inevitably this will affect the outcome measures that are used. These factors must be considered carefully in the planning and evaluations of support for carers of people with dementia.

### **The challenges of conducting research in a non-face-to-face context**

All outcome measures were collected online, and all but one of the participant interviews were conducted over the telephone, with one being face-to-face. Due to the fact that I collected data remotely, I felt somewhat detached from the data collection process; I was able to sit at home and wait for survey responses to come through, and interviewed seven participants from the comfort of my own home. I also felt somewhat powerless in terms of recruitment; although I managed to recruit sufficient numbers of participants, there were times during data collection when it seemed that there might not be enough participants. Apart from asking the Talking Point Manager to advertise the research on the Alzheimer's Society's Facebook and Twitter pages, there was not much that I was able to do in order to improve recruitment.

A benefit of online recruitment was that more participants could be recruited and they came from a wide geographical area, including some participants who were

resident outside of the UK. Given that Talking Point is an online support forum, it was appropriate to ask users to complete the survey online, and indeed there is an argument that online interventions should be evaluated online in order to maximise validity (Murray et al., 2009). This method also brought with it a number of challenges, however. I had to trust that participants did indeed meet the inclusion criteria for the study as I was not able to meet them and assess this personally (Wright, 2005). Five participants were excluded on the basis of their questionnaire responses (for example saying that they were the person with dementia rather than the carer), but there may have been others whom I missed. I do not know much about any possible differences between those Talking Point users who chose to take part in the research, and those who did not, as I did not approach them personally to take part in the research. There may well be differences between those who self-selected to take part in the research and those who decided not to (Wright, 2005). The representativeness of the research and the extent of conclusions that can be drawn are considered below.

Interviewing participants over the telephone about their experiences of being a carer and of using Talking Point was challenging. Although all interviewees talked openly about their experiences, I felt that the one face-to-face interview that I conducted generated somewhat richer data, and enabled the participant to be more open and reflective about her experiences. I felt better able to empathise when interviewing in a face-to-face context, the conversation felt more natural, and the interview easier to conduct. I was better able to make use of additional social cues, and the face-to-face context made it easier for us to react to one another (Opdenakker, 2006). Conversely, telephone interviews made it harder to create a good interview environment. I found it harder to pause to think about follow-up or

probe questions, as pausing on the telephone can be more difficult than in a face-to-face context. Several interview participants were more distracted than they would have probably been in a face-to-face context, for example, moving around their home while speaking with me. One participant was speaking with me on the phone in a small flat, and he explained that his wife was in the room as well, and so he did not feel able to say everything that he would have liked to. It may be that better quality data, or perhaps different data, would have been gathered by interviewing participants face-to-face. Interviewing people over the telephone is, however, likely to be more cost effective, and can reach a wider number of participants, so does provide a number of practical advantages.

### **The interview process**

Throughout the research process, I was struck by the openness and willingness of participants to help. Seventy-five of the initial 119 eligible participants expressed an interest in being interviewed about their experiences of using Talking Point. Most survey participants said that they wanted a summary of the research results. Although in the end she was unable to be interviewed, one participant expressed willingness to be interviewed even when one of her two sisters suffering from dementia had recently died. Some interviewees asked for their £10 “thank you” voucher for being interviewed to be donated to the Alzheimer’s Society; many asked if they could help with any other research; several asked me to get back in touch if they could help with anything else in relation to my thesis; some sent me follow-up emails thanking me for the interview and wishing me all the best with my research. They were happy to be honest and open about the challenges of caring and about their difficult thoughts and feelings in relation to this. I felt encouraged that my research was of real and meaningful importance to the people that I interacted with.

Although questions could be raised about whether this group of interviewees was representative of all of Talking Point's users, my experiences of interviewing these eight individuals did give me the sense that because caring for their loved one was such a significant part of their life, they wanted to contribute to research in this area as much as possible. This helped me to feel that the research was of real value to carers, and also that it was a reflection of how highly they valued Talking Point. A number of participants also reported feeling that however pleasant other friends and family might have been, they did not really understand their struggles and the challenges that they faced, and I hope that their experience of being interviewed was, along with interacting with other carers on Talking Point, another experience of feeling understood.

#### **The extent of conclusions that can be drawn from the research**

The number of potential participants who chose to take part in the research was estimated to be as low as 3%, and this certainly raises questions about the representativeness of the sample in the present research. These sampling issues limit the extent to which findings and conclusions can be generalised. In order for research into online peer support to be as beneficial as possible, it is important that the issue of low response rates in surveys is given some attention and that ways of increasing participation in such research are considered.

In the second survey, participants self-reported their usage data from over the 12 week study period. Initially, I emailed each participant at fortnightly intervals to obtain their usage data, but this did not yield sufficient responses to provide any meaningful data. It was therefore decided to include overall usage questions in the final survey. Although this inevitably generated more data than the initial strategy, the accuracy of this data must be considered; apart from those who never visited the

forum, remembering number of forum visits and minutes spent on the forum over a 12 week period could only ever be approximate at best. Correlational data investigating changes in outcome measures and usage level may therefore not be very meaningful.

Overall, reported forum usage levels were low. Although this may well be representative of new users of Talking Point, this does mean that outcome data is based on limited levels of forum use. This provides another possible explanation for why changes in anxiety and depression were not found after 12 weeks of forum access or usage. It is likely that the 17 people who reported that they had not used Talking Point at all over the 12 week study period visited Talking Point once and signed up, but then decided not to make use of it. This may be the pattern of behaviour for a number of people visiting online support forums, perhaps investigating the forum and then deciding not to make use of it. Although research with new users allows for measurement of outcome at baseline before the forum has been used, and again after a period of forum usage, it may be that future research is better conducted with existing users of forums, who are established in their use of the forum and have made the decision to engage with it.

This research did not have a control group. The use of a control group would have made it easier to draw conclusions from the quantitative data and meant that it may have been clearer whether any changes in outcome could be attributed to usage of, or access to, Talking Point. When researching interventions such as Talking Point that are freely available, however, it is likely that any control group participants may well have simply found another online support forum or freely available support mechanism to make use of.

### **Future research**

I hope that research into informal, non-professional types of helping will continue to develop, and I hope that the present research has highlighted the value of mixed-methods research in understanding more about both the processes and outcomes of online peer support. Research in this field is complicated by a number of factors, including the fact that most users will be accessing other forms of support, the fact that people may use such forums for a range of different reasons and so derive different individual benefits, and there will be vastly different levels of forum usage and engagement. Future research would benefit from having large sample sizes and investigating whether different types of carers both seek and derive different benefits from online peer support forums, whether online peer support works particularly well when used in conjunction with other specific interventions, and what are the specific factors that lead to positive changes for carers.

### **Summary**

Online support forums for carers of people with dementia provide a number of practical and logistical advantages over more traditional support mechanisms. The present research suggests that some of these benefits are unique to online peer support. There are a number of challenges associated with research in this area that need to be considered in order that future research into this growing area is as effective as possible.

## References

- Magnusson, L., Hanson, E. & Nolan, M. (2005). The impact of information and communication technology on family carers of older people and professionals in Sweden. *Aging and Society*, 25, 693-713.
- Murray, E., Khadjesari, Z., White, I.R., Kalaitzaki, E., Godfrey, C., McCambridge, J., Thompson, S. & Wallace, P. (2009). Methodological challenges in online trials. *Journal of Medical Internet Research*, 11, 2, e9.
- Opendakker, R. (2006). Advantages and disadvantages of four interview techniques in qualitative research. *Forum: Qualitative Social Research*, 7, 4, Art. 11.
- Schulz, R. & Martire, L.M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry*, 12, 3, 240-249.
- Schulz, R., O'Brien, A.T., Bookwala, J. & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates and causes. *The Gerontologist*, 35,6, 771-791.
- Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L.M., Belle, S.H., Burgio, L., Gitlin, L., Coon, D., Burns, R., Gallagher-Thompson, D. & Stevens, A. (2002). Dementia caregiver intervention research: In search of clinical significance. *Gerontologist*, 42, 5, 589-602.
- Torti, F.M., Gwyther, L.P., Shelby, R., Friedman, J. & Schulman, K. (2004). A multinational review of recent trends and reports in dementia caregiver burden, *Alzheimer Disease and Associated Disorders*, 18, 2, 99-109.
- Vitaliano, P.P., Young, H.M., Russo, J., Romano, J. & Magana-Amato, A. (1993). Does expressed emotion in spouses predict subsequent problems among care

recipients with Alzheimer's disease?. *The Journals of Gerontology*, 48, 202-209.

Wright, K.B. (2005). Researching internet-based populations: Advantages and disadvantages of online survey research, online questionnaire authoring software packages, and web survey services. *Journal of Computer-Mediated Communication*, 10, 3, article 11.

**Appendix 1:**

**Downs and Black (1998) quality assessment checklist**

## Appendix

### Checklist for measuring study quality

#### Reporting

1. *Is the hypothesis/aim/objective of the study clearly described?*

yes	1
no	0

2. *Are the main outcomes to be measured clearly described in the Introduction or Methods section?*

If the main outcomes are first mentioned in the Results section, the question should be answered no.

yes	1
no	0

3. *Are the characteristics of the patients included in the study clearly described?*

In cohort studies and trials, inclusion and/or exclusion criteria should be given. In case-control studies, a case-definition and the source for controls should be given.

yes	1
no	0

4. *Are the interventions of interest clearly described?*

Treatments and placebo (where relevant) that are to be compared should be clearly described.

yes	1
no	0

5. *Are the distributions of principal confounders in each group of subjects to be compared clearly described?*

A list of principal confounders is provided.

yes	2
partially	1
no	0

6. *Are the main findings of the study clearly described?*

Simple outcome data (including denominators and numerators) should be reported for all major findings so that the reader can check the major analyses and conclusions. (This question does not cover statistical tests which are considered below).

yes	1
no	0

7. *Does the study provide estimates of the random variability in the data for the main outcomes?*

In non normally distributed data the inter-quartile range of results should be reported. In normally distributed data the standard error, standard deviation or confidence intervals should be reported. If the distribution of the data is not described, it must be assumed that the estimates used were appropriate and the question should be answered yes.

yes	1
no	0

8. *Have all important adverse events that may be a consequence of the intervention been reported?*

This should be answered yes if the study demonstrates that there was a comprehensive attempt to measure adverse events. (A list of possible adverse events is provided).

yes	1
no	0

9. *Have the characteristics of patients lost to follow-up been described?*

This should be answered yes where there were no losses to follow-up or where losses to follow-up were so small that findings would be unaffected by their inclusion. This should be answered no where a study does not report the number of patients lost to follow-up.

yes	1
no	0

10. *Have actual probability values been reported (e.g. 0.035 rather than  $<0.05$ ) for the main outcomes except where the probability value is less than 0.001?*

yes	1
no	0

#### External validity

All the following criteria attempt to address the representativeness of the findings of the study and whether they may be generalised to the population from which the study subjects were derived.

11. *Were the subjects asked to participate in the study representative of the entire population from which they were recruited?*

The study must identify the source population for patients and describe how the patients were selected. Patients would be representative if they comprised the entire source population, an unselected sample of consecutive patients, or a random sample. Random sampling is only feasible where a list of all members of the relevant

population exists. Where a study does not report the proportion of the source population from which the patients are derived, the question should be answered as unable to determine.

yes	1
no	0
unable to determine	0

12. *Were those subjects who were prepared to participate representative of the entire population from which they were recruited?*

The proportion of those asked who agreed should be stated. Validation that the sample was representative would include demonstrating that the distribution of the main confounding factors was the same in the study sample and the source population.

yes	1
no	0
unable to determine	0

13. *Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?*

For the question to be answered yes the study should demonstrate that the intervention was representative of that in use in the source population. The question should be answered no if, for example, the intervention was undertaken in a specialist centre unrepresentative of the hospitals most of the source population would attend.

yes	1
no	0
unable to determine	0

*Internal validity - bias*

14. *Was an attempt made to blind study subjects to the intervention they have received ?*

For studies where the patients would have no way of knowing which intervention they received, this should be answered yes.

yes	1
no	0
unable to determine	0

15. *Was an attempt made to blind those measuring the main outcomes of the intervention?*

yes	1
no	0
unable to determine	0

16. *If any of the results of the study were based on "data dredging", was this made clear?*

Any analyses that had not been planned at the outset of the study should be clearly indicated. If no retrospective unplanned subgroup analyses were reported, then answer yes.

yes	1
no	0
unable to determine	0

17. *In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls ?*

Where follow-up was the same for all study patients the answer should yes. If different lengths of follow-up were adjusted for by, for example, survival analysis the answer should be yes. Studies where differences in follow-up are ignored should be answered no.

yes	1
no	0
unable to determine	0

18. *Were the statistical tests used to assess the main outcomes appropriate?*

The statistical techniques used must be appropriate to the data. For example non-parametric methods should be used for small sample sizes. Where little statistical analysis has been undertaken but where there is no evidence of bias, the question should be answered yes. If the distribution of the data (normal or not) is not described it must be assumed that the estimates used were appropriate and the question should be answered yes.

yes	1
no	0
unable to determine	0

19. *Was compliance with the intervention/s reliable?*

Where there was non compliance with the allocated treatment or where there was contamination of one group, the question should be answered no. For studies where the effect of any misclassification was likely to bias any association to the null, the question should be answered yes.

yes	1
no	0
unable to determine	0

20. *Were the main outcome measures used accurate (valid and reliable)?*

For studies where the outcome measures are clearly described, the question should be answered yes. For studies which refer to other work or that demonstrates the outcome measures are accurate, the question should be answered as yes.

yes	1
no	0
unable to determine	0

*Internal validity - confounding (selection bias)*

21. *Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?*

For example, patients for all comparison groups should be selected from the same hospital. The question should be answered unable to determine for cohort and case-control studies where there is no information concerning the source of patients included in the study.

yes	1
no	0
unable to determine	0

22. *Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?*

For a study which does not specify the time period over which patients were recruited, the question should be answered as unable to determine.

yes	1
no	0
unable to determine	0

23. *Were study subjects randomised to intervention groups?*

Studies which state that subjects were randomised should be answered yes except where method of randomisation would not ensure random allocation. For example alternate allocation would score no because it is predictable.

yes	1
no	0
unable to determine	0

24. *Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?*

All non-randomised studies should be answered no. If assignment was concealed from patients but not from staff, it should be answered no.

yes	1
no	0
unable to determine	0

25. *Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?*

This question should be answered no for trials if: the main conclusions of the study were based on analyses of treatment rather than intention to treat; the distribution of known confounders in the different treatment groups was not described; or the distribution of known confounders differed between the treatment groups but was not taken into account in the analyses. In non-randomised studies if the effect of the main confounders was not investigated or confounding was demonstrated but no adjustment was made in the final analyses the question should be answered as no.

yes	1
no	0
unable to determine	0

26. *Were losses of patients to follow-up taken into account?*

If the numbers of patients lost to follow-up are not reported, the question should be answered as unable to determine. If the proportion lost to follow-up was too small to affect the main findings, the question should be answered yes.

yes	1
no	0
unable to determine	0

*Power*

27. *Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?*

Sample sizes have been calculated to detect a difference of x% and y%.

	Size of <i>smallest</i> intervention group	
A	<n <sub>1</sub>	0
B	n <sub>1</sub> -n <sub>2</sub>	1
C	n <sub>3</sub> -n <sub>4</sub>	2
D	n <sub>5</sub> -n <sub>6</sub>	3
E	n <sub>7</sub> -n <sub>8</sub>	4
F	n <sub>8</sub> +	5

**Appendix 2:**

**Ethical approval**



Dr Joshua Stott  
Department of Clinical, Educational and Health Psychology  
1-19 Torrington Place  
UCL

26 March 2012

Dear Dr Stott

**Notification of Ethical Approval**

**Ethics Application 3571/001: The impact of an online support forum for carers of people with dementia**

I am pleased to confirm that your study has been approved by the UCL Research Ethics Committee for the duration of the project i.e. until October 2013.

Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form'.

The form identified above can be accessed by logging on to the ethics website homepage: <http://www.grad.ucl.ac.uk/ethics/> and clicking on the button marked 'Key Responsibilities of the Researcher Following Approval'.

2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. Both non-serious and serious adverse events must be reported.

**Reporting Non-Serious Adverse Events**

For non-serious adverse events you will need to inform Helen Dougal, Ethics Committee Administrator ([ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)), within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair of the Ethics Committee will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

**Reporting Serious Adverse Events**

The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

On completion of the research you must submit a brief report (a maximum of two sides of A4) of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

With best wishes for the research.

Yours sincerely

**Professor John Foreman**  
Chair of the UCL Research Ethics Committee

Cc: Isobel McKechnie

UCL Research Ethics Committee, c/o The Graduate School, North Cloisters, Wilkins Building  
University College London Gower Street London WC1E 6BT  
Tel: +44 (0)20 7679 7844 Fax: +44 (0)20 7679 7043  
ethics@ucl.ac.uk  
www.ucl.ac.uk/gradschool

### **Appendix 3:**

#### **Example of discussion thread on Talking Point**



**Appendix 4:**

**Screenshot of research advertisement on Talking Point homepage**

Alzheimer's Society | Leading the fight against dementia

Alzheimer's Society Website | Alzheimer's Society Factsheets | Alzheimer's Society Helpline

Forum Home | Blogs | Register Now!

Today's Posts | Calendar | Community | Forum Actions | Quick Links | Help

Forum

Welcome to Talking Point - Alzheimer's Society's online forum.

Talking Point is an online support and discussion forum, for anyone affected by dementia. It's a place to ask for advice, share information, join in discussions and feel supported.

If you would like to join a discussion on the forum or start a new one, you will need to either [register](#) or log-in (you can log-in by clicking on the box at the top right of the main forum).

If you need help using Talking Point, please take a look at our [Help videos](#) or main [Help](#) section.

Talking Point is kindly funded by Santander, who have chosen to support Alzheimer's Society as their Charity of the Year.



Are you a new user of Talking Point?

Would you like to take part in some web-based research about your early experiences of using Talking Point?

We are looking for new users of Talking Point to help us understand more about which elements of the forum users find helpful, and which elements they find less helpful.

This is a research study based at University College London.

If you are interested in taking part, please click [here](#) to be taken to the research website, where you can learn more about it.

Any information that you supply will be used by University College London for research purposes within the terms of the Data Protection Act 1998. It will not be supplied to third parties.

Talking Point  
Welcome to Alzheimer's Society's Talking Point forum.

Support from other members



**Appendix 5:**

**Information sheet as seen on survey website**

## Welcome to the Talking Point Survey!

Thank you for  
thinking about taking part.

### Information sheet for participation in research study

#### **The impact of an online support forum for carers of people with dementia**

You are invited to take part in a research study based at University College London (UCL). This page contains information about the study to help you to decide whether or not to take part.

#### What is the purpose of the research?

This study aims to further understand whether online forums such as Talking Point are helpful for the people who use them, and if so, in what ways.

We hope that 100 people will take part in the research.

#### Who can take part?

In order to take part in the research, we ask that you are:

- A new user of Talking Point, on your first visit to the forum
- An 'informal carer' for a relative or friend with dementia (i.e. you are not paid)
- The main carer of the relative or friend with dementia
- Over 18 years old
- An English speaker

#### Do I have to take part?

It is completely up to you whether to take part. Your participation is entirely voluntary and a decision not to take part will have no effect on your use of the forum or anything else. In fact, nobody apart from you will know that you have decided not to take part. You can also drop out of the study up until you fill in the final questionnaires or until interviews are typed up, and again, there will be no penalty to you if you decide to do this.

#### What will it involve?

There are two parts to the study. Everyone who decides to take part in the study will do the first part, and some will also be invited to do the second part (if they wish to).

#### *Part 1 of the study*

The study begins by asking you to fill in some short questionnaires online about your mood and your experiences of caring. These should take no more than ten minutes to complete.

We will also ask for your email address. This is just so that we can keep in touch with you about your use of the forum, and about the questionnaires. We will not pass it on to anyone else, and your data will be anonymous when the results come out.

You can then use Talking Point as much or as little as you like. We will email you every two weeks asking for a quick summary of how much you have used the forum. This is not a test – we are just interested to know how often people go online and how they make use of Talking Point.

After three months, we ask you to fill in the questionnaires online again.

For most people, this is where the study ends.

#### *Part 2 of the study*

For the second part of the study, 15 participants who have done part 1 of the study will be invited to take part in an interview (lasting about one hour) about their experiences of using Talking Point. For people in the London area, these interviews can either be face-to-face or over the phone. For people outside of London, the interview would be over the phone. If you wish to do part 1 of the research, you do not have to volunteer to do part 2 - it is optional.

#### What happens after the study?

After the study, you will be able to see the results online.

#### Are there any risks?

We do not anticipate any risks to participants who take part in the research. If anything does happen to you as a result of taking part in this research, you can contact Vicky Bennett from the research team at [talkingpointresearch@hotmail.co.uk](mailto:talkingpointresearch@hotmail.co.uk) or by telephone on . Alternatively, you can contact Dr Joshua Stott, a member of the research team, on .

#### How will the data be stored?

Data will be collected and stored in accordance with the Data Protection Act 1998. We will store your email address and the information that you give us in the questionnaire, as well as your information about your use of the forum. This will be stored in a secure location and only the research team will be able to see this. The data will be kept for five years after publication and then disposed of in a secure manner.

For those who take part in the second part of the research, interviews will be audio recorded and then typed up and made anonymous. Recordings will then be erased. The interview texts will be kept for five years after publication and then disposed of in a secure manner.

#### Will I be identifiable when the results come out?

You will not be identifiable in the results of the study. We are collecting your email address only in order to keep in touch with you about your use of the forum, and also to arrange an interview if you decide that you would like to do this. All results will be anonymous and any information gathered from interviews will not be identifiable.

#### Who has reviewed this study?

This research study has been approved by the UCL Research Ethics Committee, which is a group of independent people.

#### Who has reviewed this study?

This research study has been approved by the UCL Research Ethics Committee, which is a group of independent people.

#### Further information and contact details

Thank you for considering taking part in the research. If you have any questions or concerns, or would like a paper copy of this information sheet posted to you, you can email me (Vicky Bennett) at [talkingpointresearch@hotmail.co.uk](mailto:talkingpointresearch@hotmail.co.uk), or by telephone on . Alternatively, you can contact Dr Joshua Stott on .

Start

**Appendix 6:**

**Consent form as seen on study website**

**Informed consent for participation in research study: The impact of an online support forum for carers of people with dementia**

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 3571/001

Thank you for your interest in taking part in this research. Before you agree to take part, the person organising the research must explain the project to you. If you have any questions arising from the Information Sheet, please ask the researcher before you decide whether to join in. You can print out a copy of this Consent Form to keep and refer to at any time.

**Participant's statement:**

I have read the notes written above and the Information Sheet, and understand what the study involves.

I understand that if I decide that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately, up until the time when I submit my final questionnaires, or until my interview is typed up.

I consent to the processing of my personal information for the purposes of this research study.

I understand that such information will be treated as confidential and handled in accordance with the provisions of the Data Protection Act 1998.

I understand that the information I have submitted will be published as a report and that this will be available for participants to view online. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.

I agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

*There are two parts to this research. The first involves filling in some questionnaires, and the second involves taking part in a one hour interview about your experiences of using Talking Point. You can just do part 1 if you want to.*

Please check this box to confirm that you agree with the statements above. Checking this box indicates you giving your informed consent to take part in Part 1 of the research and will take you on to the first part of the research (i.e. filling in the questionnaires).

YES I consent to take part in this study

**NOTE: Please do not press the "Back" button when completing the survey, as you will lose the survey!  
If you wish, you can click on "Save and return to survey later" so you can come back to the survey later.**

Save and return to survey later

Next

**Appendix 7:**

**Email sent to those who scored in the “severe” range on GAD-7 and/or PHQ-9**

Dear [name],

Many thanks for taking part in the UCL research study, 'The impact of an online support forum for carers of people with dementia'. As you will probably remember, the research began with you filling in some questionnaires about your mood and about caring.

As part of our ethical requirements for the project, it is our duty to contact people whose questionnaire scores indicate that they may be experiencing somewhat higher levels of distress. Your replies to the questionnaires suggested that you might be feeling distressed and that you might find it helpful to seek additional support. If you do feel that professional help would be beneficial, you may find it useful to visit your GP and speak with them about this.

If you would like to talk over why you have been sent this email, or if you have any other questions about this email or the research in general, you are welcome to contact me by replying to this email.

Best wishes,

Vicky McKechnie, MSc  
Trainee Clinical Psychologist

**Appendix 8:**

**Demographic questions as seen on survey website**

Talking Point

These questions ask a bit about you and your background.

4. Are you...

- Male
- Female

5. How old are you? Please type in your age.

I am  years old

6. What is your ethnic group?

- WHITE: English / Welsh / Scottish / Northern Irish / British
- WHITE: Irish
- WHITE: Gypsy or Irish Traveller
- WHITE: Other
- MIXED / MULTIPLE ETHNIC GROUPS: White and Black Caribbean
- MIXED / MULTIPLE ETHNIC GROUPS: White and Black African
- MIXED / MULTIPLE ETHNIC GROUPS: White and Asian
- MIXED / MULTIPLE ETHNIC GROUPS: Other
- ASIAN / ASIAN BRITISH: Indian
- ASIAN / ASIAN BRITISH: Bangladeshi
- ASIAN / ASIAN BRITISH: Pakistani
- ASIAN / ASIAN BRITISH: Chinese
- ASIAN / ASIAN BRITISH: Other
- BLACK / AFRICAN / CARIBBEAN / BLACK BRITISH: African
- BLACK / AFRICAN / CARIBBEAN / BLACK BRITISH: Caribbean
- BLACK / AFRICAN / CARIBBEAN / BLACK BRITISH: Other
- OTHER ETHNIC GROUP: Arab
- OTHER ETHNIC GROUP: Any other
- Prefer not to say

7. What is your highest qualification or level of education?

- Primary school
- GCSEs or equivalent
- A Levels or equivalent
- University degree (BA / BSc)
- Higher degree or equivalent
- Other (please state)

8. Are you...

- Retired
- Unemployed
- Employed (If so, please state your occupation)

9. If you are retired, what was your occupation?

10. Who is the person with dementia that you are caring for? If you are caring for more than one person with dementia, please tick all the boxes that apply to you.

- Partner
- Mother
- Father
- Grandparent
- Daughter
- Son
- Aunt or uncle
- Neighbour or friend
- Other (please state)

11. Approximately how long have you been caring for this person? Please write in years and months (for example, 5 years 2 months).

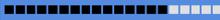
12. Are you currently accessing any formal support in relation to caring for your relative or friend (for example, NHS memory clinic, support from GP)?

- No
- Yes (Please state what support you are receiving)

13. Are you currently accessing informal support in relation to the person that you are caring for? This might include, for example, other internet forums, religious groups, or emotional/practical support from friends/family.

No

Yes (Please say a little about what this support is)



Save and return to survey later

Next

Powered by  
[Opinio Survey Software](#)

## **Appendix 9:**

**The scale for the quality of the current relationship in caregiving**

Please think about your relationship with the person you are caring for and answer the following questions by ticking the appropriate box. <i>Please tick <b>one</b> box in each row.</i>	Totally disagree	Disagree	Not sure	Agree	Totally agree
1. My relative and I often spend time together in an enjoyable way.					
2. My relative and I often disagree.					
3. There is a big distance in the relationship between my relative and myself.					
4. My relative and I accept each other as we are.					
5. If there are problems my relative and I can usually resolve these easily.					
6. I get on well with my relative.					
7. My relative and I are tender towards each other.					
8. My relative often annoys me.					
9. I feel very good if I am with my relative.					
10. My relative and I often try to impose our opinions on each other.					
11. I blame my relative for the cause of my problems.					
12. My relative and I appreciate each other as people.					
13. My relative does not appreciate enough what I do for him/her.					
14. I am always glad to see him/her if I have not seen him/her for some time.					

**Appendix 10:**

**GAD-7 questionnaire**

<b>Over the last 2 weeks, how often have you been bothered by the following problems?</b>	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

**Appendix 11:**

**PHQ-9 questionnaire**

<b>Over the <u>last 2 weeks</u>, how often have you been bothered by the following problems?</b>	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure — or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving .around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

**Appendix 12:**

**Interview schedule**

## **Interview Schedule**

Thank you for agreeing to speak with me today about your experiences of using Talking Point. I expect that the interview will take about an hour, during which time I'll be asking you some questions about your experiences. I know that we will be talking about things that could be upsetting, and I want this interview to feel comfortable for you. If there are any questions that you would rather not answer, that is absolutely fine. And if you wish to stop the interview at any stage, this is also fine. The interview will be audio recorded and I will later type up this conversation. But it will be anonymous because you will not be identified by name. Instead you will be given a participant number?

Do you have any questions before we begin?

### *Introductory questions:*

1. How would you describe your main experiences of being a carer? Main difficulties and struggles?
2. What made you want to visit Talking Point?

### *Overall comments on Talking Point:*

3. Generally, how do you feel about Talking Point?
4. Is there anything that you like or find particularly useful?  
*Prompt: Why is it useful?*
5. If you have posted on Talking Point, what led you to decide to make your first post?
6. Is it more useful to read about others' difficulties or seek support with/post about your own difficulties?
7. Is there anything that you do not like about Talking Point?

*Prompt: Why not?*

8. Is there anything that you have not found useful?

*Prompt: Why not?*

*Experiences while using Talking Point:*

9. How much do you feel part of Talking Point?
10. How much do you feel that other users are similar to you?
11. Do you feel that Talking Point is dominated by certain people, or do lots of different people have a voice?

Do you think that the frequent users set the tone for the site? Or set any unwritten rules about how the site is used?

12. It seems that Talking Point is used in a number of different ways. Some of the posts relate to information, advice and practical issues that people need support with, such as advice about bed rails. Posts also include more emotionally supportive comments, such as encouraging and supporting someone else who is struggling. How do you find the balance of practical support and emotional support on Talking Point?

a) Is one more helpful to you than the other?

b) Do you make use of one more than the other?

c) When you read other people's posts, do you have any preference for reading practical/emotional messages?

13. Would you say that there are any specific things about being on Talking Point that you find particularly helpful?

*Prompt: e.g. knowing that there are other people in the same position / imparting or receiving information / feeling part of the group/ feeling able to help others / sharing experiences / being able to be honest with people...*

14. Any things that you find particularly unhelpful?

Prompt: e.g. feeling criticised or disrespected / content of posts making you feel worse, e.g. from hearing about others' difficult experiences.

15. Do you feel safe using Talking Point?

Prompt: Do you have concerns about privacy or confidentiality?

*Outcomes after using Talking Point:*

16. Has Talking Point has made a difference to you?

Prompt: Any positive differences? Any negative differences?

17. Have you learned anything from using Talking Point?

18. Has Talking Point changed the way that you feel about yourself as a person?

19. Has Talking Point changed the way you feel about yourself as a carer?

20. Has Talking Point changed the way that you see the person you are caring for?

21. Has Talking Point changed your actions in any way?

a) Behaviour towards person who you are caring for?

b) Other relationships?

*Other:*

22. What would you say to someone who was thinking of using Talking Point?

Prompt: How would you describe Talking Point to a friend?

23. Any other comments?

24. Do you have any questions?

25. How did this interview feel?

Explain £10 voucher which I will post. Would you like this? It will contain a subject payment form which I need you to sign and send back. Don't worry, although the form has a list for

many names and addresses, I will not send it to other participants, so they will not have your name and address. It is just so that the voucher can be covered on expenses. Thank you for your time.

**Appendix 13:**

**A sample section of coded interview transcript**

Initial coding	Transcript	Theme
<p>Reading how father may become → initial concern, but...;</p> <p>There will be someone out there having a worse day; Getting positive comments from someone else who is suffering; Supporting others → feel better;</p> <p>Going on to TP just to read posts;</p> <p>TP gives me strength;</p> <p>Talking to others in the same situation</p> <p>Mum won't use TP. She'd feel less alienated if she did</p> <p>Making friends</p> <p>TP gives you what you need at any particular time</p> <p>Feeling like you're the only one</p>	<p>P3: I mean the first time I was just reading other views thinking, oh god, is it going to be that bad, or, but then you do get strength from it, and even if you're having a bad day, there is someone else out there having a worse day. So you can find yourself getting positive comments on there from someone else who is suffering, even though you are feeling it as well. If you boost somebody else, it makes you feel better in yourself anyway. So it's a really good... I go on there just to read, not necessarily post, but...</p> <p>I: You've said a little bit, but generally, how do you feel about Talking Point?</p> <p>P3: I like it. I see it as a strength to me. It gives me strength. It is something that I can look into and I know that I am talking to people in the same situation, so it's definitely good. And the fact that you go on there and there's quizzes, and there's... I mean, my mum won't use it, because she's scared that my dad will look at it or see it. My dad is not computer literate. But I think my mum would gain a lot from it [I: Yeah]. She wouldn't feel so alienated if she used it. But I just do like it. And you almost make friends. It's almost like a Facebook, because you can put pictures on it. And if someone's gone missing, it's there, you can help and support. I think it's a fantastic support network. No, yeah, really good.</p> <p>I: And is there anything that you like or find particularly useful about Talking Point?</p> <p>P3: To be honest I only really go on the chat forum page. I have looked at the, I think there's a recipe page, there's a joke page, and the joke page can be quite amusing if you're feeling really... So that's quite cheerful, but there's not a negative or a plus, it's just something that you can key into that has something there that will give you what you need at that particular time.</p> <p>I: You talked a little bit about posting. Have you yourself posted on Talking Point?</p> <p>P3: I have.</p> <p>I: And one thing that the Alzheimer's Society were quite interested to learn about was what it was that led people to make their first post if that makes sense, to take that leap and make a post.</p> <p>P3: I think somewhere along the line when there's somebody who's a carer for someone who's got dementia, you do feel terribly alone, and you feel like you're the only one that's in that situation. So it's somewhere that you can, it's someone you can talk to, you can say, I mean I think my first one was, you know, I keep thinking that I want my dad to die, and I would never want my dad to die. But it's something I could put on there, but I didn't have to</p>	<p>Other posts can be distressing</p> <p>Other users are worse off; Being able to support other users;</p> <p>Not necessarily needing to post to benefit</p> <p>Not the only one going through this</p> <p>Reduced isolation</p> <p>Reduced isolation</p> <p>Anonymous/not face-to-face</p>

**Appendix 14:**

**Sample interviewee feedback form**

## Talking Point Research – Participant feedback form

### Participant 7 summary

Below are themes that I drew out from our interview, including some illustrative quotes

- Theme: Talking Point provides information  
Quote: *“our first reaction is, something is going on, we research it. Which is part of why I joined up with Talking Point. We find out as much as we can about what’s going on”*
- Theme: Being able to compare experiences to those of others  
Quote: *“To find out how other people are finding things and you know, if my reactions are similar to others or if it’s me that’s out of kilter with things, or, you know, is what I’m feeling normal, do other people find similar difficulties”*
- Theme: Many users of Talking Point are in worse situations. This helps you to feel that you should be able to manage your situation  
Quote: *“my goodness, some people are dealing with some incredibly difficult situations. And how on earth do they cope? And those situations, my goodness, the situation we’ve got at the moment is not that difficult, we ought to be able to work around it. We ought to be able to sort things out between us without wringing our hands and saying this is far too difficult.”*
- Theme: Talking Point provides information about what the future might look like and one can then plan  
Quote: *“And just gleaning more and more information, and information about how the disease might progress. So in terms of information, things that are relevant to us right now, but also these are the sort of things we need to be thinking about. You know, let’s not just wait for a crisis and then try and sort things out. Let’s think in advance, what will we do in this situation, so it’s not just reactive, it’s proactive as well”*
- Theme: Everyone has experience. This can provide information and support  
Quote: *“what’s useful is that it is a group of peers, so that anything you say, somebody’s going to have come across something similar... I think that’s very supportive”*
- Theme: Talking Point provides support that might not be available from family  
Quote: *“My major difficulty as being the daughter-in-law, where [on Talking Point] I’ve felt I’ve been able to get emotional support which is not available within the family because people don’t see, see my role differently”*
- Theme: You can control what you read  
Quote: *“I think if I look at the posts and it’s not useful, then I don’t read all of the replies and stuff. So I find it’s very easy to navigate and to from the titles pick up things that might be useful”; “you make your choices by what you read and what you respond to”*
- Theme: Talking Point as compared to a more “conventional” service  
Quote: *“Well, it was while I was away that this discussion within the family about the POA was going on, so I was able to link in through Talking*

*Point and post the question even though I was physically many thousands of miles away. So you know, that was extremely useful”; “particularly with me being mobile around the world as well as around the country, it’s offered a support that I wouldn’t have had otherwise”*

**How much did the themes listed capture your views from the interview?**

Please underline the number that best matches your answer.

<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
Not at all	A little	Moderately	Quite a lot	Completely

**Was there anything missing from the list of themes?:**

**Was there anything that needs changing?:**

**Any other comments:**