

The experiences of counselling and psychotherapy from the perspective of carers of people with dementia: an exploration of client views and processes of change

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Executive summary

Introduction

The National Dementia Strategy (2009) highlights the significance of family carers in supporting people with dementia. However, supporting a person with dementia at home often has a significant emotional, physical, social and practical cost to the person providing this support. Counselling/psychotherapy can be a valuable resource in the lives of carers of people with dementia. This study aimed to explore the experiences of therapy from the perspectives of carers of people with dementia – to our knowledge, narratives that had yet to be heard.

Methods

Six participants took part in the study. Semi-structured interviews were undertaken with participants to explore a range of topics, including their everyday experiences, their expectations/experiences of therapy, and the impact of therapy on their lives. A holistic-content narrative analysis was used to interpret the data.

Results

A series of six case studies is presented. Two main themes emerged: i) understanding helpful therapeutic interventions; and ii) understanding the therapeutic relationship/non-specific factors within therapy.

Discussion

The following topics are raised: changes in the relationship with the person with dementia, the dynamic nature and longevity of the caring situation, characteristics that may be over-represented in carers, growth, service issues, issues regarding the therapeutic relationship/non-specific factors within therapy, and the ways in which carers make sense of therapy alongside the goals of clinicians.

Key findings/recommendations

- The therapeutic relationship can provide: i) a 'substitute' for the changed parts of a relationship between a person with dementia and their relative; ii) a space for validation and support; and iii) a place in which a carer can develop a more independent 'sense of self'.
- Understanding, trust and genuineness are important for building successful client-clinician relationships.
- Clinicians should carefully consider the arguments within the literature on the issue of self-disclosure. Supervision should be used to reflect on this issue.
- Data from the current study lend weight to the use of a range of therapies with carers of people with dementia. The therapeutic relationship and the use of formulation enable therapeutic interventions to fill a need for carers of people with dementia, which may not be met by other support services.
- Clinicians may find it useful to explore literature in the area of stress-related growth when working with carers of people with dementia.
- Clinicians should be aware of certain characteristics that may make people vulnerable within the caring role. These characteristics include people who: i) have a strong sense of responsibility for others; ii) gain satisfaction from supporting others; and iii) see others' needs as more important than their own.
- Clinicians may find compassion-focused therapy helpful if there are elements of shame/guilt within feelings expressed by carers.
- Therapy can be a valuable place for support for a carer if a person with dementia is moving into a care setting.
- Carers do not always find it easy to ask for help; advertising availability of services is important in order to improve access to counselling/psychotherapy.

Introduction

The most commonly occurring dementia in older and younger people is Alzheimer's disease (Alzheimer's Society, 2007), although there are many different causes of dementia, which vary in their presentation and progression. A recent Alzheimer's Disease International report (Prince, Bryce & Ferri, 2011) has suggested that there are currently 36 million people with dementia and their families worldwide, with this number expected to rise significantly as the world's population ages. The report called for early diagnosis of dementia to enable people with dementia and their carers/families to take advantage of appropriate support programmes and services.

According to the Dementia UK report, the greatest risk for the acquisition of dementia is increasing age, with one in five people aged over 80 having a form of dementia (Alzheimer's Society, 2007). It is estimated that there are currently 683,597 people with dementia in the United Kingdom (UK); this is representative of one person in every 88, or 1.1% of the entire UK population (Alzheimer's Society, 2007). However, the Dementia UK report acknowledges that this may be a slight underestimate, as its figure did not fully address the context of people with learning disabilities or people with dementia in NHS continuing care environments.

The instigation and implementation of the National Dementia Strategy (NDS) in England (Department of Health, 2009) marked a significant step forward in public awareness, perception and expectation about 'living well' with dementia. Objective 7 of the NDS is concerned with 'implementing the Carers Strategy for people with dementia'. This objective reminded its audience that there are over 500,000 family members in England who care for a person with dementia, and that carers provide over £6 billion a year worth of unpaid care. It is, therefore, perhaps unsurprising that objective 7 of the NDS (Department of Health, 2009) acknowledges that 'family carers are the most important resource available for people with dementia' (p. 49), and states that carers have a right to interventions which support the important role that they play in the care of the person with dementia.

Supporting and caring for a person with dementia at home often comes at a significant emotional, physical, social and practical cost to the person providing this support. Over the years, the negative impact of providing care on a carer's psychological and physical wellbeing has been consistently documented across numerous studies. For example, carers of people with dementia are particularly vulnerable to depression (Gallagher-Thompson et al, 2000), 22% experience low mood (Mausbach, Patterson & Grant, 2008), and rates of anxiety range from 16%-45% (Cooper, Katona, Orrell & Livingston, 2006). Higher levels of stress and psychological distress are found in carers of people with dementia compared with other groups of carers (Pinquart & Sorensen, 2003), and caring for a person with dementia has been found to be more stressful than providing support for someone with a physical disability (Ory, Hoffman, Yee, Tennstedt & Schulz, 1999).

The issues pertinent to supporting a person with dementia are likely to include coping with a person's cognitive decline and changes in their behaviour, as well as dealing with changes in intimate relationships between a person with dementia and their relatives (Kneebone & Martin, 2003). Almgren, Grafstrom and Winblad (1997) found that carers describe three main categories of strain: 'memory difficulties', 'changed behaviour', and 'feelings of loss and new roles'. These issues can lead to stress and distress, but new adaptive coping strategies can be developed through the use of psychological help and support from professionals (Downs & Bowers, 2008).

Counselling and psychotherapy for carers of people with dementia

Mittelman, Roth, Clay and Haley (2007) argue that counselling and support may prevent a decline in health in caregivers of people with dementia, and the results of a systematic review by Gallagher-Thompson and Coon (2007) found that the largest average effect size in a range of psychological interventions was within the psychotherapy category, particularly cognitive-behavioural approaches. There are various other examples within the literature, which demonstrate the impact of cognitive-behavioural interventions for carers on anxiety (Cooper, Balamurali, Selwood & Livingston, 2007), depression (Marriott, Donaldson, Tarrier & Burns, 2000), and anger (Buchanan, 2004). It is important to note, however, that when comparisons are made between various therapeutic approaches, none appears more favourable than any other (Wilson, Mottram & Vassilas 2008). Whilst the number of very recent empirical studies that focus specifically on counselling/psychotherapy is small, multicomponent psychological interventions within which therapy is a component, demonstrate impact on the wellbeing of those taking part (Elvish, Lever, Johnstone, Cawley & Keady, 2012).

A number of studies give insight into the processes of change within therapy with carers of people with dementia. Following therapy, studies have identified more collaborative views of the future between partners (Auclair, Epstein & Mittelman, 2009), changes in awareness (Sørensen, Waldorff & Waldemar, 2008), and changes in attitudes (Auclair et al, 2009; Sørensen et al, 2008). On the first point, collaboration is suggested to be underpinned by the development of more accepting, non-judgemental and non-blaming attitudes (Auclair et al, 2009). Sørensen et al (2008) suggest that counselling for carers of people with dementia provides 'opportunities for caregivers to engage in early reflections that might create changes in awareness and attitudes, which may result in better coping' (p. 449). Informed by the work of Folkman's (1997) stress and coping model, Sørensen et al (2008) argue that the mediators in the change processes of counselling interventions may be due to the occurrence of more positive psychological states. Furthermore, other work has defined concepts such as 'role investment', suggesting that therapy can help to address loss of personal identity, which can result from the caring role interfering with other roles that are important to a person (Barton, Armstrong, Freeston & Twaddle, 2008).

Since the turn of the new century, the use of technology to support the delivery of counselling and psychotherapy interventions has significantly increased (Drigas, Koukianakis & Papagerasimou, 2011). For example, recent literature contains high quality studies with significant outcomes in the areas of burden and quality of life following the use of telephone counselling sessions (eg Belle et al, 2006; Lee, Czaja & Schulz, 2010; Nichols, Martindale-Adams, Burns, Graney & Zuber, 2011). Technology-based interventions offer potential benefits to carers who do not utilize services for logistical reasons; for example, not being able to find support for the person with dementia to enable the use of a service by the carer (Bank, Argüelles, Rubert, Eisdorfer & Czaja, 2006), being based in a rural area (Glueckauf et al, 2005), and having other appointments to attend (Bank et al, 2006). However, on the down side, much of the current older adult population does not have access to technologies such as computers, or access to suitable and age-appropriate training (Wade & Wolfe, 2005). Developments in clinical practice must therefore continue to be flexible. Further work into the impact of technology-based interventions will not only deepen understanding about technology-based interventions *per se*, but will also give further insight into the ways in which the therapeutic relationship influences outcomes.

In summary, research suggests that counselling/psychotherapy can impact on the wellbeing of carers of people with dementia, particularly interventions underpinned by cognitive-behavioural theory. To date, literature gives insight into the processes involved in counselling/psychotherapy interventions for carers of people with dementia, but this area needs further exploration.

Client experiences of therapy

Much of the research undertaken within psychotherapy has been carried out from the perspective of the therapist (Rodgers, 2002), and there remains a limited literature about client experiences and expectations of therapy. Berg, Raminani, Greer, Harwood & Safren (2008) argue that identifying important aspects of therapy from client perspectives will: i) aid development of treatment; ii) aid understanding of barriers and facilitators to engagement in therapy; and iii) help further understanding of the processes of change within therapy. Within the limited literature that exists, perspectives on the experience of therapy from specific client populations include reflections from clients with HIV (Berg et al, 2008), and from gay, lesbian, bisexual and transgender individuals (Israel, Gorcheva, Burnes & Walther, 2008). In terms of findings from this work, Elliott (2008) points to the two most helpful aspects identified by clients as 'facilitative therapist characteristics' and 'client self-expression'. Other areas of importance include: a supportive therapeutic relationship (Mörtl & Von Wietersheim, 2008), achieving self-understanding (Elliott, 2008), an empathic or validating therapist (Israel et al, 2008), and being offered specific techniques for problems by a therapist (Safren, 2008). Elliott (2008) goes on to state that 'it also seems to me that this literature is now mature enough to offer a kind of general baseline against which to look for issues specific to particular client populations' (p. 241). To the best of our knowledge, obtaining experiences of therapy from the perspectives of carers of people with dementia are narratives that are yet to be heard.

The aims of this study were to explore the meaning of counselling/psychotherapy from the perspective of carers of people with dementia, and to explore the processes of change within therapy through the interpretation of this data.

Methods

Participants

Following the research protocol, inclusion criteria were as follows:

- participant has a relative who has received a diagnosis of dementia
- participant provides care to a person with dementia
- participant over the age of 18
- participant speaks English.

Participants were required to be undertaking counselling/psychotherapy, defined for the purpose of this study as:

- 1:1 or family sessions (not group sessions)
- work planned to be undertaken over at least six sessions
- sessions undertaken by a professional registered with either the Health Professions Council or the British Association for Counselling and Psychotherapy.

In addition, it was necessary for a clinician to determine that the therapeutic work had arisen primarily as a result of a carer's response to their relative receiving a diagnosis of dementia, or as a consequence of the impact of their relative's dementia.

Eight services (community mental health teams and memory services) in the North West of England were informed about the study. Clinicians identified potential participants and informed them about the study. If interest was expressed, the potential participant's details were passed on to two members of the research team (RC/RE) so that they could be provided with further information. Six carers were contacted with further information; all agreed to participate. The recruitment figure of six carers was below the recruitment target for the study. One reason for this appeared to be that the number of carers of people with dementia on clinicians' caseloads was not as high as anticipated. No clinician indicated that they had clients with whom they did not feel it was appropriate to share details of the study, but two clients declined to take part.

The participant sample consisted of five females and one male. The female participants consisted of three spouses and two daughters. The male carer was a spouse. The age range of the participants was 55-80 years old. All participants described themselves as White British.

The clinicians were two counsellors and two clinical psychologists who all worked within specialist older people's services. For the remainder of this text, the term 'therapy' refers to both counselling and clinical psychology interventions, and the terms 'therapist' and 'clinician' are used interchangeably to refer to counsellors and clinical psychologists.

Design

The study was designed as a qualitative piece of work using semi-structured interviews. Interviews were conducted at one time point only; however, one participant's interview occurred across two sessions. RC and RE undertook interviews within participants' homes across a four-month period. Interviews were audio recorded and transcribed on completion. The duration of the interviews ranged from 61-120 minutes. The length of the interview was an interesting outcome from this study; our sense was that participants wanted to share their story and needed time and space to do this. It was as if the experience of therapy could only be made sense of through a biographical grounding of participants' (caring) experience, which in itself was embedded within their own narrative and sense of identity. In many ways, the anticipated need that each of the participants would have to 'tell their story' influenced and informed the choice of methodology that underpinned the study (narrative analysis), with the detail shaped under an 'intra' and then 'inter' case study approach to data reporting.

The semi-structured interview guide was informed by previous studies that explored client experiences of therapy in different populations (Berg et al, 2008; Israel et al, 2008). In addition, studies by Mackenzie (2006), Sørensen et al (2008), and Simon and Nelson (2004) were also drawn from. The interview was split into two main topics. Firstly, participants were asked about their current activities of everyday life and the social relationships within their lives. Following this, participants were asked about their expectations and experiences of therapy (including the therapeutic relationship), how they would describe therapy to a friend, what had been helpful/unhelpful, and the impact of therapy on their life (see Appendix 1 for full interview guide). Whilst the interview guide was used to structure the conversation, the interviewer, using techniques such as summarising, explored topics of interest further. In addition, at the beginning of each interview, a quantitative depression questionnaire was completed by each participant to give a measure of mood. The questionnaire used was the Center for Epidemiologic Studies Depression Scale (CES-D), a depression scale widely used for research purposes (Radloff, 1977). A measure of depression was undertaken in order to support analysis/interpretation of client data, and to facilitate risk assessment.

The clinician for each participant was asked to complete a two-item questionnaire (Appendix 2). Clinicians were asked to identify the theoretical approaches underpinning their therapeutic work, and the goals for therapy from their perspective.

Data analysis

Interviews are the most frequently chosen method of data collection when using narrative approaches (Williams & Keady, 2008). A narrative analysis allows the individual story to emerge (Riessman, 1998), but although 'story' and 'narrative' are terms used interchangeably, not all story is narrative whereas narrative includes story (Paley & Eva, 2005). In other words, it is the content of the story that is the unit of analysis, and that facilitates thematic representation from within a biographical discourse. As the carers' data were structured around the sequencing and reporting of a series of detailed individual case studies, the study team adopted an 'holistic-content' approach to narrative analysis to guide the work and its reporting (Lieblich, Tuval-Mashiach & Zilber, 1998). In applying this approach, a 'case study' draws upon the general emergent themes and direction from the narrative story (Lieblich et al, 1998). This is achieved through reading (and/or listening) to the material several times until a pattern emerges focused on the whole story and its context. This results in an initial overview of the story and of any exceptions that challenge a 'first impression' of the data, as well as accounting for any unusual features. A particular focus or theme is then identified that seems to dominate the text from beginning to end, either spatially, by being repetitive, or through the depth of description (Lieblich et al, 1998). These themes are coded, marked and re-read separately.

For the carers' data, therefore, our first task as a research team (RE/RC/JK) was to read and independently code the first transcript, particularly looking for explanatory themes that summarised the holistic content of the narrative. On meeting to discuss the outcome of this initial exercise, agreement was reached on the contents of a coding frame that included initial ideas on the data and its thematic impression. The coding frame was built on and developed as additional transcripts were read. After several readings of all transcripts by each member of the team, a final coding frame was agreed that acted as a template for processing, organising and interpreting the data. The results of these exercises inform the direction and content of the findings section.

Ethical considerations

The project was reviewed and given a favourable opinion by North Manchester Ethics Committee. Approval to undertake the project was received from Greater Manchester West Mental Health NHS Foundation Trust, Merseycare NHS Trust, and Pennine Care NHS Foundation Trust. All carers and clinicians gave informed consent to participate in the study. The carers' names in the findings section of this paper are all pseudonyms.

Findings

Case study 1

Background/context

June was a 68-year-old retired woman. She described herself as White British. Her husband, Harry, received a diagnosis of dementia four and a half years prior to her undertaking her research interview. She had defined herself as a carer from the time Harry received his diagnosis. June and Harry received support from a care agency once a fortnight for three hours.

June and Harry had been married for 11 years. It was a second marriage for them both. At the time of the interview, June was experiencing some health difficulties herself. She had received a recent diagnosis of breast cancer and had undergone an operation requiring a general anaesthetic, she'd had a serious fall, and she was having some problems with her eyesight.

At the time of the interview, June had been undertaking weekly counselling sessions with a female counsellor for three months. She had her counselling at home, and found this very helpful because she did not have to think about support for Harry.

On the CESD, June scored within the range for mild to moderate depression.

Daily life

June described significant recent changes in her and Harry's lives: i) the revoking of Harry's driving licence, which had led to dependence and changes in the kinds of holidays they could take; ii) changes in the ways June and Harry spent time together as a couple due to Harry's changing abilities; iii) changes in the time June spent on her hobbies; and iv) loss of confidence, particularly for Harry.

Social relationships

June did not describe close and supportive relationships with her siblings, which was a longstanding situation. She described a good relationship with her father, and this was also true of Harry's relationship with his father-in-law. Harry had not been in contact with his own children for approximately nine years prior to June's interview.

June felt that it had taken time for some friends to acknowledge the difficulties that Harry was experiencing. She described how hard it was when friends would make comments that reflected a lack of understanding about their situation:

‘ That sort of flippancy can really, it can really dig deep, it really can.’

The relationship with the person with dementia

Whilst a change in the dynamics between June and Harry had clearly occurred following Harry's diagnosis, a sense of 'togetherness' in their relationship juxtaposed, perhaps encircled, other changes. June talked about the continuing love between her and Harry, and described the ways in which they worked together on problems that arose. June also spoke positively about changes in roles arising as a result of Harry's dementia. For example, she described roles that she had taken on because of Harry's cognitive difficulties. This had led to: i) a sense of achievement that she felt when she had undertaken new tasks; ii) a positive

feeling for her when Harry expressed how proud he was of her for doing new things, and iii) a development in trusting herself.

Changes that were more difficult for June included the strain of being with Harry for 24 hours a day, the loss of verbal contact with him, the sense of responsibility she felt for Harry, and the way that the 'dependence' in their relationship meant significant planning was required to undertake many aspects of daily life.

Expectations

June spoke of plans that she and Harry had made following their wedding and the impact of life not turning out quite as planned:

'It's impossible not to feel, I wouldn't say resentment but, you know, a bit fed up sometimes.'

'The happiness edge has gone out of our lives a bit although we try not to let it, you know.'

June also stressed that, alongside dealing with the impact of Harry's dementia, the rest of life continued to make demands on her. She described dealing with other difficult aspects of life, and expressed a fear of doing something in case something else went wrong. The following quotation encapsulates not only the theme of expectations, but also the feeling of the previous sections:

'It's so difficult because life's going on all the time and things do change sometimes for the better, sometimes for the worse, but they do change.'

Therapy: the clinician's perspective

June's clinician described her approach as humanistic and integrative. From the clinician's perspective, the goals for therapy were:

- supporting, processing, identifying and understanding the impact of loss, grief and life adjustments in conjunction with Harry's health and June's own health
- identifying with and managing continual change, in relation to the 'self', and Harry's self, and the 'together self'
- working with recurring and increasing concerns, and finding helpful ways of coping with what is now and what may be ahead.

Therapy: the client's perspective

June defined a therapist as:

- A trained person. This was important for June because she believed that a trained person would have an understanding, and an ability to 'read into' things. She also felt that a friend might be worried about what they said to you, but this would not be an issue for a trained person with no personal connections. This would therefore result in a 'better answer' from the therapist.
- Someone who draws out your feelings, particularly about what you want in terms of help, support and information.

- Someone who listens, and who you know is listening. Someone who sometimes interrupts in order to give you an explanation as to why you are experiencing certain feelings/emotions, and to explain the reasons why you might be feeling those things.

June felt that therapy provided a space where she could offload her concerns and voice her fears. She described her clinician as giving her an explanation of things in a different way, in a way that had not occurred to her previously. Sessions enabled June to reflect with her therapist, and also resulted in her thinking about things afterwards. The sessions usually left her feeling quite good, even if she had not 'changed her mind' about things. She described feeling more confident after talking about things, and she had used some of the visual representations that had been used in her sessions when she was on her own. June felt that having therapy was particularly important, as she did not have a close personal relationship within which she could share her thoughts and feelings.

Initially, June agreed that she would input into the planning of sessions. However, shortly after beginning therapy she received a diagnosis of breast cancer. This resulted in her feeling that the sessions were 'coping' with that, and so they had been more spontaneous/led by the therapist. June did not usually know in advance what would occur in a session. She did not plan in advance what she wanted to say, and there was a sense that this was partly because things in life were often changing, so she never knew what would be the most 'significant' issue. June was clear that she felt comfortable not knowing what a session would 'look like' until it occurred.

The therapeutic relationship

June spent a significant amount of the research interview reflecting on the relationship with her clinician:

'So I feel that in that way we've got a really good relationship there and through that obviously it's going to help me.'

'For quite a while afterwards I feel quite good about things and I can think about things that we've talked about, and I'm not saying that it doesn't change my mind about the way I feel but at least I've spoken about it.'

The following points summarise the important aspects of the therapeutic relationship for June:

- A therapist must be somebody who can be related to. Whilst this was difficult to quantify, June elaborated by saying 'she is very similar to me in [her] approach about things... there's no flannelling about her at all.' For June, it was important to 'see something of yourself' in the therapist.
- A therapist must be genuine. Although another difficult concept to quantify, June described qualities such as being consistent, open, understanding and easy to communicate with.
- A therapist must be someone who can be trusted. June expanded on this by saying that she needed to feel able to trust that her therapist was committed to doing something good for her, and that her therapist would deliver.

The characteristics outlined in the above three points were more important to June than knowing that a therapist had experienced a similar situation to her own.

Case study 2

Background/context

Arthur was a 76-year-old retired male teacher. He described himself as White British. His wife, Mavis, received a diagnosis of dementia around two years prior to him undertaking his research interview. Mavis had had a stroke 22 years previously, and Arthur defined himself as a carer since that time. Mavis had recently moved into permanent care following a period of assessment; Arthur visited her every day for about 30 minutes. At the time of the interview, Arthur was attempting to contact an independent support service.

Regarding his own health, Arthur had received a diagnosis of prostate cancer and he also reported some hearing problems.

At the time of the interview, Arthur had been attending fortnightly NHS counselling sessions with a female counsellor for around 12 months. His sessions were held at a local centre, which provided a range of support services for people with dementia and families, and he was happy with the practical arrangements for his sessions.

On the CESD, Arthur did not score within the clinical range for depression.

Daily life

Significant changes in daily life described by Arthur included: i) being extremely busy, particularly in relation to work in the home because Mavis was no longer living there. Tasks he undertook included washing, changing the duvet, and cooking. At the end of a day he described feeling physically very weak; ii) changes in the types of holidays he could take with Mavis. He described planning a holiday to a place that could meet their needs, but highlighted that there were places that they used to visit but could no longer go to; and iii) feeling lonely in the evenings and when eating alone.

Social relationships

Arthur described the relationships with his children as supportive, but he also acknowledged the complexity of relationships when he described his worries about his children's lives and the impact that their behaviour had on his own life. He did not receive good support from his wife's family, which resulted in him feeling angry.

Arthur described supportive relationships with friends. He did not really talk about 'issues' with them, but having them made a difference. In addition, Arthur also had a female friend who had been through similar circumstances to him. This friendship gave him a space to talk more about his current situation, which he valued greatly.

The relationship with the person with dementia

Arthur enjoyed some of the new tasks he was engaging in, such as cooking. He also reflected that he was now the sole decision maker, and he liked to think that Mavis would be pleased that he was 'making it':

'Yeah, I enjoy it. I rather enjoy it... and at the end of the day, this is a bit sad this, really, I like to think that Mavis, well Mavis will never come home, but I'm making it, I suppose, so that she would really like...'

The relationship with formal services

Arthur felt uncertain about whether Mavis would come home, despite describing her as being in permanent care. He reported that she wanted to come home, that she was a strong-willed person, and therefore that there was a possibility that she might return home. He was fearful about this, believing that neither of them would cope.

Arthur described excellent support from services whilst Mavis was at home and during her transfer into care. However, since Mavis's move to care Arthur felt that he had no one to share his concerns with:

'They've [the professionals undertaking diagnosis] ticked their little box and that's it... and washed their hands of us.'

Therapy: the clinician's perspective

Arthur's clinician described her approach as using person-centred non-directive therapy, working with the core conditions of unconditional positive regard, empathy and congruence.

From the clinician's perspective, the therapy goals were for Arthur to:

- acknowledge new aspects of himself
- work through his feelings
- accept and gain increased insight and self-understanding
- prioritise his thoughts/anxieties
- work towards an understanding of the changes in his situation.

Therapy: the client's perspective

Arthur's definition of a therapist was:

- Someone who does not ask you any questions or tell you anything, but allows you to talk and 'wander around all kinds of blind alleys' so that you can hear yourself and work out what is important for you.
- A trained person.
- Someone who is listening and can demonstrate that they are listening. Not someone who is just 'looking out of the window and looking at her watch'.

Arthur felt that therapy was a space to get things off his mind. It was a place where he could work out what was important and a priority for him, and he felt that it had given him confidence and hope. He was unsure whether his therapist planned the sessions in advance; he sometimes reflected on what he would like to talk about before a session.

Arthur had undertaken therapy before his current experience. He was referred to a psychologist following his wife's stroke, and more recently had six sessions before being referred to his current therapist. He also had experience of counsellors in his professional life; this had made him suspicious and cynical about this type of work. His previous experiences had influenced his expectations and opinions about his current therapy as follows: i) Arthur's previous psychologist had used self-disclosure on many occasions. This had resulted in Arthur feeling that the person could not keep a lot to themselves, and that

they did not have an open mind; ii) Arthur's previous therapist had written lots of notes during the sessions, which he found off-putting, and resulted in him feeling guarded. His current therapist did not do this, which he found much better; and iii) Arthur's previous therapist had been a lot younger than the person he was currently working with. Alongside feeling more open with his current therapist, this led him to make judgements about the qualifications of each of the therapists and the 'grading' system that must be in place:

'I think he was... he was only quite young.'

When asked to rate his therapist on a scale of 0-10 (10 being best possible), Arthur gave her 10. He said that he would recommend counselling to a friend in a similar situation, but acknowledged that it was probably not for everyone. A significant theme that emerged for Arthur was ensuring that people were aware of the availability of counselling services. He was not initially aware of what was available, and felt that services should be brought to people's attention as early as possible.

Finally, when discussing additional things that he would find helpful in his counselling, Arthur said that he sometimes thought of things between sessions, which he would like to discuss but then forgot to do so. He suggested that it might have been helpful if his therapist had given him the idea of writing down things between sessions.

The therapeutic relationship

For Arthur, the important aspects of a therapeutic relationship were as follows:

- A therapist must be trusted. For Arthur, this meant being able to tell them anything, without holding back. The things that enabled Arthur to build trust included believing that the information he shared would remain confidential, and not feeling that any judgements were being made by his therapist (even if they were):

'You feel that she's taking everything in, making no judgement. She doesn't make any judgement at all. I mean, she might think I'm talking an awful lot of crap at times. I'm sure she must be making some internal judgements, but she never shows any sign of an adverse reaction, which I think is very encouraging.'

- A therapist must put you at ease, and enable you to share as much as possible:

'She's very, what's the word, coaxing in a sense. She's very, you know, gentle coaxing, even by nodding sometimes, so I think really, she's quite excellent really at making you say as much as you possibly can say really.'

Case study 3

Background/context

Cybil was an 80-year-old retired woman. She described herself as White British. Her husband, Tom, received a diagnosis of fronto-temporal dementia within the 12-month period prior to her interview. However, she described his difficulties as beginning about three years earlier. Prior to the research interview, Tom had recently begun attending a specialist day service for people with dementia. Cybil did not describe herself as a carer.

During her interview, Cybil described some significant life events. One of these was the death of her son; when talking about this she shared how she had coped and made sense of her grief. She also spoke about physical and mental health difficulties that she had experienced, particularly highlighting the impact that stigma around mental health issues had on her at the time.

At the time of interview, Cybil had been undertaking fortnightly NHS counselling sessions with a female counsellor for around one month. She had undertaken two sessions prior to her interview, and was happy with the practical arrangements of home visits. Her referral for counselling had been made by an occupational therapist who had undertaken an assessment with Tom; she had not considered counselling prior to this.

On the CESD, Cybil did not score within the clinical range for depression.

Daily life

Cybil described her life as busy, although acknowledged that she could only be as busy as her health would permit. She described changes within her life as: i) changes in her husband's memory abilities; and ii) changes in the way she and Tom spent their time together; they no longer socialised at their local club, and Tom had stopped going shopping and placing a bet on the horses.

Social relationships

Cybil described close relationships with her family:

'I'd be completely lost without my family.'

She talked about the importance of friends providing companionship, and described a neighbourhood in which you could call on people if you needed them:

'Well, we've got young neighbours that's come in, they're very sociable, very good, and if you went to them and said, you know, could you help, they'd be there.'

The relationship with the person with dementia

Cybil did not talk much about her relationship with Tom. However, when describing their life she said that he had 'always been there'. She appeared to be expressing that she had been the one who had needed support during their lives together, but now the roles had switched somewhat:

'[Tom's] always been there. It's been me that's been the one that's been in hospital and what have you, right.'

She also spoke about changes in her role now that Tom was unable to do many things:

‘And I’m saying to [Tom], them windowsills upstairs, right, inside, they could all do with all redoing, right. In the past, he would have done it himself.’

Therapy: the clinician’s perspective

The clinician took a non-directive and person-centred approach, using the core conditions of person-centred therapy.

From the clinician’s perspective, the therapy goals were for Cybil to:

- accept the changes in her situation
- manage and move forward in a positive way.

Therapy: the client’s perspective

Cybil did not know what counselling would entail before she began her sessions. She looked forward to her therapist coming, and said that she put her at ease and helped her to share things:

‘She helps give you some time to be you, some time to talk about things, some time to just get them out in the open.’

Cybil felt that her therapist was one strand in a support structure that appeared to hold an equal amount of weight to other forms of support:

‘I think she’s just another cog in a wheel, really. I mean, it’s just, it’s like a cake, there’s sections for everything to make a cake. And, I mean, I’m not just benefiting because I’m having counselling, I can’t see where that, just that alone, is going to give me the help and support that I need. I’ve got the help and support from my family, my friends, my neighbours, you know.’

Once Cybil had built a relationship in therapy, she appeared to view the relationship as providing similar things to her other relationships; in her current situation, this meant that counselling provided a substitute for part of the relationship that she no longer had with Tom, and provided an additional relationship to her other support networks:

‘I just sit and chat. Yeah, I do. Yeah, we just hold a conversation. But it’s nice to hold a conversation with someone, right. Because I can’t have a conversation with [Tom].’

‘Well, I mean, at first, you know, when she got her things out and started asking questions and that, you know, then it did seem, you know, very like going to the doctors. But now, it doesn’t. It just, to me, it’s just like another friend turning up for a natter.’

Cybil did not plan in advance what she wanted to say, and whilst she was unsure whether her therapist planned the session ahead, she thought that she came in with a ‘blank slate’.

When asked to rate her therapist on a scale of 0-10 (10 being best possible), Cybil said that she would describe her as nearer 10 than 0. She said that she would recommend counselling to a friend if they wanted it, but acknowledged that it was not for everyone:

‘I don’t think it’s for everybody because I don’t think, I mean, there’s a lot of people don’t want people to come in their house.’

The therapeutic relationship

Although Cybil did not talk about the therapeutic relationship in detail, she commented on the importance of the relationship:

'I mean, you don't want somebody coming that rubs you up the wrong way, you know. And, I mean, that can happen.'

Case study 4

Background/context

Susan was a 66-year-old retired woman. She described herself as White British. Her mum, Alice, received a diagnosis of dementia six months prior to Susan's research interview. However, Susan described Alice's cognitive difficulties as beginning around five years before that. At the time of the interview, Alice was residing in an assessment unit. Before this, she had received home care four times a day. Susan had defined herself as a carer for three years.

Susan's second husband died 12 years before her interview; following his death, she had some hypnotherapy.

At the time of the interview, Susan had undertaken three fortnightly NHS therapy sessions with a male clinical psychologist. Her referral was made by an occupational therapist. Susan's sessions were at a local hospital that provided outpatient and inpatient services for older people. Susan felt happy with this arrangement as it 'made' her go out of the house.

On the CESD, Susan scored within the range for major depression.

Daily life

Susan described recent significant changes as being related to the progression of Alice's cognitive impairment and the transition into receiving a diagnosis of dementia:

'I noticed that she was getting more and more confused, and I mentioned it to the GP and nothing seemed to happen. But it was as last year was going on, I could see Mum was getting... she wasn't washing herself, she wasn't changing her clothes and I knew she wasn't sleeping in bed.'

Susan began doing shopping and washing for Alice, but she described finding it incredibly difficult when home carers would telephone her for advice. When she made a decision to support a move for her mum to undergo a period of assessment, she found this very difficult:

'I always said to my mum I would never ever put her in a home. So when I was asked about Mum going to [the assessment unit] that was a really, really hard decision to make.'

At around the same time, Susan's mother's brother, Ernie, was also suffering from Parkinson's Disease:

'So I could see Mum was getting worse, so that was upsetting me, and then [Ernie's] Parkinson's, that was getting worse as well. So I think I just felt I was losing control.'

Susan described her coping strategies:

'I used to sob and sob and sob. And every Saturday I used to treat myself. I don't drink a lot; I used to buy myself a small bottle of strong beer. I'd just drink it while I was preparing something to eat for myself, then I'd go for a long soak in the bath.'

Susan had bought herself a dog some years ago after completing her hypnotherapy sessions, and her pet appeared to be an important part of her life.

Social relationships

Susan lived by herself, and described how hard this could be when she was coping with difficult times:

'[I was dealing with mum and Ernie] and then coming home to an empty house, coming home to an empty house and nobody to say... I know lots of people live on their own, but I think when you've not chosen to live on your own, that's hard as well.'

At the time of the interview, Susan did not have contact with her daughter. She saw her grandchildren regularly but this was not always easy, as she sometimes had to travel to see them.

The importance of receiving understanding from others was highlighted within the contrast that Susan described between those who provided validation, and those who did not:

'Because I think if you tell people that you're depressed and you're on antidepressants I've heard people say oh well, you've got to pull yourself together, just sort yourself out. I find it quite hurtful actually. I won't tell them anymore how I'm feeling, I'll just keep it to myself.'

'The doctor said that you can become really, really poorly if you don't talk about your problems or whatever is upsetting you. In fact he's told me that even though I go to see him every two weeks, if I want to go and see him in the meantime to just go... knowing that somebody understands what you're actually going through.'

'Yes, there is a lady I've got friendly with, she walks her dogs, so I've become friendly with her, and she's a widow. So we understand.'

The relationship with the person with dementia

Prior to Alice's dementia, Susan described her relationship with her mum as one that contained tension:

'There's been a lot of friction and tension over the years, yes. I was frightened of my mum.'

However, she talked of dementia changing the relationship between them:

'I think if she didn't have dementia and it was just the ageing process, I think our relationship would still be more or less the way it was before. But it has changed, it has changed compared to the way it used to be.'

For Susan, this change appeared to have had both a positive and negative impact on her. Despite finding some of her mum's characteristics difficult in the past, she shared that:

'I miss the way even though she used to be grumpy and cross, I miss all that, because she was full of spirit.'

Regarding the positive outcome of the change in their relationship, Susan said:

'When she was okay she'd always ask what time I'd be turning up... [if] it got late, she'd have a go at me. Whereas now when I go to see her she's so pleased to see me, it's amazing the difference. But that's because she's got no realisation of time or anything. I think that's the main reason, but she's really relaxed and there's no anxiety, all that's gone.'

Alongside the positive and negative outcomes of the change in their relationship, Susan also spoke of the grief that she felt for the person that Alice used to be:

'It's been hard, really, really hard. Because she's not the woman she used to be, and in a way, even though she's still here you're grieving for the person the way they used to be.'

Finally, Susan spoke of how she has learned to interact with both her mum and Ernie now, by stepping into their worlds:

'I step into her world. I've learnt to do that with [Ernie]. I think he's starting with dementia. So I step into his world, but then it's a different world to the world that Mum's in as well. So I've learnt to do that, step into their world.'

Therapy: the clinician's perspective

Given the complexity of the history between Susan and Alice, the clinician initially drew from a cognitive-behavioural model to identify Susan's capacity for change. Following this, the approach combined schema therapy and personal construct therapy wherein the experimental aspects of change and the increased potential for a developed sense of self were explored concomitantly. Of note, the approach was partly dictated by the number of sessions provided to Susan (two assessment sessions and six intervention sessions).

The goals for therapy from the perspective of the clinician were to:

- provide Susan with an increased sense of self in order to identify the emotional traps which she fell into that led to the absolute subjugation of her own needs to those of others
- enable Susan to make more informed choices regarding which aspects of her life she wished to change, and to behave in a less automatic and more self-aware way
- help Susan experience that she could love or like herself without having to be loved by someone else
- shift Susan's belief that you can only be loved if you say yes every time someone asks you to do something.

Therapy: the client's perspective

Although Susan had previous experiences with a hypnotherapist, she was unsure what to expect from a clinical psychologist:

'I wasn't sure actually, I suppose it's because I'd never met a psychologist before. And I knew it wouldn't be like meeting a counsellor, and I knew it wouldn't be anything like when I used to go and see [the hypnotherapist].'

Susan described her therapist as someone who asked questions and gave their perspective. At the beginning of her sessions, the total number of sessions was agreed in advance. She said that her therapist planned the sessions in advance, and she felt there were goals for the sessions. Susan was sometimes given 'homework' in between sessions, including writing about herself in the third person and behavioural tasks. Following sessions, she was left thinking about what had been talked about:

'Every time I see him my head's buzzing with everything that we've been talking about. And I'm thinking over what we've been talking about, what has been said.'

Susan shared that her therapist helped her to focus on herself, rather than her helping others, which was what she usually did:

'And he's helping me to focus on me, which is something people don't do. So he's helping me focus on me, and trying to help me, myself, rather than what I normally do, helping other people.'

One of the main ways in which therapy had impacted upon Susan's life was that she had stopped saying 'yes' so much, and had started saying 'no' to people. The benefits of this were both practical and emotional: i) Susan felt that she had more time for important appointments, including appointments for her dog; and ii) Susan felt better about herself:

'I think he's shown me that to say no to somebody doesn't mean that I'm a bad person.'

When asked to rate her therapist on a scale of 0-10 (10 being best possible), Susan felt she would describe him as 9. She said that she would recommend therapy to a friend, but recognised that it was not for everyone:

'I'm not sure it's for everybody, because there are a lot of cynical people out there.'

Understanding psychological theory

During her interview, Susan demonstrated awareness and understanding, which had developed during her therapy sessions. She discussed terms used within cognitive models such as 'the bottom line', and she talked about the importance of childhood experiences and predisposing factors:

'Every reaction has a reason, I can see that and he's explained to me that how you were treated as a child affects you right through your adulthood. Because that's part of you, isn't it? So if someone says something to you, he's shown me that you react in the way you would do as a child.'

The therapeutic relationship

Throughout her interview, Susan stressed the importance of 'understanding' within relationships, including the therapeutic relationship. She said that, initially, she had believed that someone needed to have experienced something to be able to understand. However, following the second session with her therapist, she felt that he demonstrated understanding despite not being in a similar situation (to the best of her knowledge):

'I came away from that meeting thinking he doesn't understand; he doesn't understand what I am going through. I came away from the second meeting and I thought, he gets me.'

Susan felt that trust was vital within the therapeutic relationship. She described the importance of being put at her ease, and the qualities that helped her to build trust:

'Whoever I meet I've got to trust them. If I don't trust them I tend not to say much and keep very quiet... [my therapist is] very honest, he's very open, he understands me. I think it's trust more than anything, he's very open, he's friendly. I think we've got a good connection.'

Case study 5

Background/context

Julie was a 55-year-old nurse who worked 30 hours a week, including 12-hour shifts. She described herself as White British. Her father, Bert, received a diagnosis of dementia 13 years prior to Julie's research interview. Julie described herself as being a carer for the past 10 years, and she had been Bert's sole carer for the last two years. At the time of the interview, Bert had recently moved into residential care. Julie visited him every day for about 60-90 minutes.

Julie moved to be closer to her family following a divorce, some years prior to her interview. Her sister died a few years before the interview.

Julie had recently completed a course of NHS counselling sessions with a female counsellor, undertaken over a 14-month period. The referral for her counselling was by an occupational therapist working with her father whilst he was living in his own home. The sessions were undertaken at a local medical centre, but Julie described the location as unsuitable:

'Awful. Both places were not suitable... the rooms were not comfortable particularly, they were very serviceable, the rooms, for what they were but not for what we were having. I didn't think it was relaxing at all.'

Julie's counsellor acknowledged to Julie at the beginning of their sessions that the room was not appropriate for their purposes. In addition, Julie stated that it would have taken her 45 minutes, using two buses, to attend the sessions if she had not been able to drive. If this had been the case, she said that she would not have attended.

On the CESD, Julie scored within the range for mild to moderate depression.

Daily life

When Julie discussed recent changes within her life, she spoke of difficulty finding balance. Prior to Bert moving into residential care, he would ring her frequently and she would visit a lot. After finding life difficult for a significant period of time, Julie subsequently took some time on sick leave:

'I think that's probably why I got like I did with my dad, because I was trying to cope with absolutely everything and not coping with anything really.'

During this period, Julie reflected on her work-life balance. She decided to return to work as a staff nurse, rather than in her previous position as a sister. This change enabled Julie to play the role in her dad's life that she wished to, and she also reflected on secondary positives from this change:

'I'm enjoying being a nurse again and not being a pen pusher... it's nice, actually, being a nurse again. I'm happier doing what I used to do, so I'm pleased about that.'

Alongside this, Julie did have to attend carefully to financial matters, and she talked of taking additional agency work to give her further income but with flexibility. Whilst it was clear that Julie was continually required to balance competing parts of her life, she seemed confident in the decisions she was taking despite not finding the decisions easy. Ultimately, she felt a sense of pride in her decisions:

'I think I've made the right decision. Well, I'm sure I have actually. I know it's the right thing. I was quite proud of myself actually, that it was a positive thing that I was doing, that I would be able to sort things out, and it has worked.'

When talking about the transfer of her dad into residential care, Julie became upset:

'It was awful. Horrible. I felt I'd let him down; it was an awful thing to do. You look at him and it's like a little boy in a grown-up's outfit. And now he's fed up, he doesn't want to be there, he wants to go home and he says it every day.'

Finally, Julie described her sense of humour as an important coping strategy:

'Yes, that's how I deal with it, I've always dealt with it like that though, I've always been that sort of person. If you can get things away with a bit of a giggle it's so much better, and it gets you out of so many situations, and people appreciate it.'

Social relationships

Julie had regular contact with her daughters, niece and nephew. She described her youngest daughter as very supportive:

'[My youngest daughter] and I get on really, really well anyway. I don't know how I'd have got on without my daughter, she's just amazing.'

Julie also described her eldest daughter as supportive, spending time with Bert to enable Julie to have a break:

'But I mean she comes out and she'll go and see her granddad and she loves it, and sometimes she'll come over on a Sunday and she'll say "right, you have a day off, Mum, and I'll go". Then that's quite nice when she does that.'

Another important person in Julie's life was a friend whose mother also had dementia. The friend validated and normalised Julie's feelings.

Despite these supportive relationships, Julie expressed a feeling of not wanting to upset others, and not wanting to share negative thoughts about Bert in case she affected the way others felt about him. She gained satisfaction from helping others, and people often came to her with their problems.

One of the main themes that emerged from Julie's interview was the impact of previous events and losses on her current feelings. Firstly, she shared that she felt that Bert's move triggered emotions related to the loss of her sister:

'I think maybe, this happening to my dad, I think it all came back a bit about [my sister], and because we were going to look after him together; and that was the problem – we couldn't.'

She went on to describe the close relationship that she had enjoyed with her sister, and the impact of her sister's death on her feelings about the current situation with Bert:

'I promised [my sister] that we would never get the social services involved, we would never put him in a home, and that's what delayed it all because I couldn't do it.'

Lastly, she shared that Bert had felt guilty when his mother moved into a care home. This had been a significant factor influencing Julie's feelings that she should not be supporting Bert's move into residential care.

The relationship with the person with dementia

Julie described her relationship with Bert as sometimes good and sometimes bad. Although he was in full-time care at the time of her interview, she continued to feel a sense of responsibility to look after him; she visited him every day, and took him to all his hospital appointments:

'I feel it's my responsibility. He might be being looked after in a nursing home, but he's my dad, and I know if my dad was well he'd look after me. So why shouldn't I look after him?'

Julie also described a change in her relationship with Bert:

'It's like a role reversal, like I'm the one in charge now and he's not, and it's wrong.'

Twice during her interview, Julie referred to a comment that Bert had made regarding being 'left' with Julie since her sister's death. This had evidently had a lasting impact on Julie, influencing her interpretations of further interactions with Bert:

'But I can't bring her back can I? But you know this thing that he said, that I'm not good enough and why is it me that's left?'

Therapy: the clinician's perspective

The clinician's approach was person-centred therapy, using those core conditions and allowing the client to explore and reflect.

The goals of therapy from the clinician's perspective were:

- for Julie to accept and live with the changes in her life
- for Julie to identify that the decisions made were the right decisions for her
- to enable Julie to move forward with her life in a positive way
- for Julie to acknowledge the changes within herself and to be able to facilitate change.

Therapy: the client's perspective

Julie's expectations of therapy were described as the emotion of dread:

'I was dreading it a bit, really. I thought, oh hell's teeth, this is going to be horrible! And it is, it's awful. I expected to go in and I expected to get upset.'

Following the first two sessions, however, Julie felt more able to talk with her therapist without becoming so upset. She described subsequent sessions as a space where she was asked questions to prompt her, where she talked through how she was feeling, and where she thought about how she would do the things that she wanted to do:

'I don't remember her offering advice at all the whole time I was with her. I think it was just my opportunity to talk through how I felt and what I wanted to do and how I was going to go about doing it.'

Julie noted that although she discussed her feelings of guilt during the sessions, this did not get rid of her guilt.

Julie described the time following sessions as difficult, but there was a sense that she did not really understand why this was:

'It wasn't necessarily the day that I'd had counselling that I felt so bad, it was the following day. You feel absolutely horrible the next day. I don't know why that is. I don't know whether it's just because you've got so emotional and you've let everything out and it's a bit of a release, maybe; I don't know.'

Julie believed that her therapist planned the sessions in advance, but did not feel that they were too structured:

'And I didn't feel like she'd got a list of questions, I felt that she knew what she needed to find out and how to get things out of me without having to look at a piece of paper, and I liked that. It was more of a chat than a structure.'

Julie found it helpful to talk to someone neutral; someone who would not be affected by the information that she shared and who would keep the information confidential:

'Yes, someone neutral, somewhere you can offload and you're not worrying that it's going to come back and bite you on the bottom at some point, because then obviously it's not going to go anywhere else, it's confidential. It's like if you tell your friend something you never know whether that friend's going to tell somebody else, and you tell your family and then you think you're putting all this burden on them and they've got enough worries themselves.'

When asked how she knew that attending therapy had been worthwhile, Julie shared the following: i) she did not blame herself for things in the way that she had in the past; ii) she felt that her sense of humour had returned; and iii) by highlighting the progressive nature of situations that carers are dealing with, she identified the importance of using what had been learnt in therapy in the future:

'But I'm so glad that I did get the counselling because it's made this bit easier now. I feel that I'm coping with what's happening now better than I would have done had I not spoken to somebody, because I think the next few months are going to be very difficult, because Dad is deteriorating.'

Julie did not remember her therapist taking notes, but said she would not have minded either way.

When asked to rate her therapist on a scale of 0-10 (10 being best possible), Julie described her as 8. She said that she would recommend therapy to other people, but discussed the importance of the public being aware of services available to them. For Julie, this related to her beliefs about coping; she did not feel that she would have instigated a referral through her own GP due to fears of feeling like a failure:

'I think it's almost like feeling a bit of a failure. I always said I was a coper, but I'm not as much of a coper as I thought I was.'

The therapeutic relationship

Julie highlighted the importance of 'getting on' with someone, and she did not feel that someone had to have experienced a similar situation to understand:

'I was very fortunate, the lady I got was absolutely lovely; she was really, really nice.'

Julie identified the following factors as important in the therapeutic relationship: i) a therapist being friendly; ii) a therapist who is welcoming; iii) a therapist who is warm; iv) a therapist with whom you feel comfortable; v) appropriate therapist self-disclosure: 'We just chatted generally about how she's got a grandchild and I've got one on the way.'; vi) age of the therapist: 'I don't know whether age would make a difference. If it was somebody very young, I [would] think: How much life experience have you got?' and vii) a therapist demonstrating that they listen, for example by remembering names or information from a previous session.

Case study 6

Background/context

Edith was a 74-year-old retired woman. She described herself as White British. Her husband, Albert, had a stroke four years prior to Edith's research interview. He was diagnosed with vascular dementia around two and a half years following this. Edith described herself as being a carer for the previous four years, since the time of Albert's stroke.

At the time of interview, Edith had undertaken NHS therapy sessions with a female clinical psychologist for nine months. A support worker made her referral. Edith's sessions were undertaken at a local hospital that provided outpatient and inpatient services for older people. Edith felt happy with this arrangement as it meant her sessions were not interrupted by telephone calls, people coming to the house, or by her husband.

On the CESD, Edith scored within the range for mild to moderate depression.

Daily life

Edith described her life as being defined by her caring role for Albert:

'A typical week, really, is basically looking after [Albert].'

She described her current daily life as typically consisting of activities that centred on Albert's care: for example, preparing meals, washing and attending appointments.

Edith also shared that recent changes had led to a reduction in her being able to do things for herself, such as having a leisurely bath, going to the hairdresser or having a good sleep.

Social relationships

Edith described good relationships with her sisters, but believed that she would receive more support from them if they lived closer. Neither her nor Albert's family lived close by.

Edith felt that her sisters understood her and demonstrated empathy; however, she highlighted that the situation with Albert was constantly changing but she felt she could not continually share her thoughts and feelings:

'Sometimes you can see a slight improvement with [Albert], or maybe not, and sometimes you think, oh he's getting worse. But I don't tell them every day about it, you know, but they do empathise, they do sympathise and they're there if I need them.'

Edith felt that the reason she needed to see her therapist was because she did not have anyone else with whom she could regularly share thoughts.

Relationship with the person with dementia

Edith implied that she found it difficult to acknowledge and accept the changes in Albert's cognitive abilities:

'I keep thinking if I push [Albert] enough, he's going to... And I really, really, really can't get it into my mind, because [Albert] looks fit and well, he looks so fit and well. He is fit and well except that he doesn't function like he did.'

Edith described her relationship with Albert as not being shared anymore; this was in relation to practical daily tasks, but she also referred to the changes in their emotional relationship which meant that she could no longer share problems with Albert. Ultimately, this made her feel that she was on her own; she found it difficult to feel confident with the responsibility that she now felt for things which previously Albert would have taken care of:

‘And if there was a problem, I could go to [Albert] with it, but I haven’t got that now, it’s different. You feel sort of... that you’re on your own.’

Edith acknowledged that her relationship with Albert had never been perfect; however, in the past there had been some good times. Whilst she described him as currently never being kind, considerate or cooperative, the strength of her love for him was also clear:

‘[Albert] was never easy to live with, but we had nicer times. Now, there aren’t any good times in between, you know what I mean, so that I find a bit draining.’

The loss of ‘equality’ that Edith felt in the relationship was epitomized when she said that she believed that if Albert behaved the way he did but was not ill, their marriage would not survive. However, because of the situation, she felt the marriage had to survive because of her love for Albert and her desire to be there for him:

‘I think if the situation was like this and [Albert] was fit and well, the marriage wouldn’t last, but the marriage has got to last now, you see what I mean, because the situation is because [Albert] isn’t well. Now, it’s got to survive now, because I love [Albert] and I’m there for him.’

Expectations

Edith described feelings of anger because her life with Albert had not turned out as they had planned:

‘I get angry... when I say angry, mad at the world, not mad, but you know this is not what we planned, sort of thing.’

Therapy: the clinician’s perspective

From the clinician’s perspective, the approaches used within the therapy with Edith were:

- psychoeducation to increase knowledge and awareness of her situation
- basic cognitive-behavioural therapy principles to manage anxiety more effectively
- elements and techniques from acceptance and commitment therapy to help Edith adjust to the changes in her life.

The goals for therapy from the clinician’s perspective were to:

- aid Edith’s understanding of Albert’s dementia and the impact of vascular dementia on him
- reduce Edith’s general anxiety levels
- provide Edith with the skills to address difficult situations more effectively
- help Edith adjust to the considerable changes that have taken place in her life.

Therapy: the client's perspective

Edith did not really know what her expectations of therapy were, but she found it less probing than she thought it would be.

In the first part of her interview, Edith said she was unsure if she would describe her sessions as 'therapy':

'I don't know if the word therapy sort of covers what we're having really, it's just like a conversation.'

As the interview progressed, it appeared that the use of the researcher's language, together with Edith's attendance for her research interview, had resulted in Edith thinking about the meaning of her sessions:

'You know, I said I have an appointment; I said it was made through [my clinician]. They said psychotherapy – what do they call it? A psychoanalyst I think they call [my clinician]. And then it hit home. Before that, it really didn't hit home that I was seeing... And it was then that I realised that in what professional basis I was seeing [my clinician], if you know what I mean.'

This seemed to result in Edith experiencing a range of quite complex feelings about the meaning of therapy; she wondered whether she really needed 'therapy', and also thought that she 'should' be able to cope with her situation without help. She appeared to make connections between the term 'therapy' and the mind not being 'all right':

'She's definitely a great help but then I think, well my mind is all right, perhaps I don't need it.'

Edith described her sessions as a place where:

- there was a friendly ear and where she could offload things
- she could gain some space from Albert
- her therapist helped her to work things out; for example, why things had happened.

She said that she did not really know what therapy was supposed to do, but it made her feel better. Her therapist provided validation, gave her confidence, helped her to live in the present rather than worrying about the future, and helped her to see the whole picture. Whilst Edith felt that her situation could not be changed, she felt that her therapist was helping her through:

'You know, nobody can make things right, nobody can alter the situation. But really, seeing [my therapist] is helping me through it. Well, there's nothing else a therapist can do really. I mean, can they alter your mind? My mind tells me to stay with my husband and help him through, despite how unpleasant it is.'

Edith acknowledged the potential longevity of her situation, and she was unsure about how long her therapy sessions would continue. However, she felt she could always phone her therapist if she needed help.

Edith did not know if her therapist planned the sessions in advance, and Edith did not usually plan what she wanted to say.

When asked to rate her therapist on a scale of 0-10 (10 being best possible), Edith said she would rate her very highly. She felt that she would recommend therapy to a friend, but acknowledged that everyone's situation was different.

The therapeutic relationship

Edith felt that her therapist put her at her ease and she found her easy to talk to. She said that she trusted her because she listened, was sympathetic and had a very nice manner.

Holistic-content narrative analysis

The aim of this study was to explore the experiences of therapy of carers of people with dementia, and the processes of change within therapy. As discussed in the introduction to this text, other recent literature has explored specific client populations in order to develop understanding of the specific needs of those client groups. The following analysis attempts to integrate the responses of the six participants in this study, in order to provide further insight into the experiences of carers of people with dementia undertaking therapy. Three main themes are discussed: issues regarding therapeutic interventions which are pertinent to carers of people with dementia; issues regarding the therapeutic relationship/non-specific factors within therapy; and understanding about how carers make sense of therapy alongside the goals of clinicians.

Issues regarding therapeutic interventions pertinent to carers of people with dementia

Changes in the relationship with the person with dementia

When a carer was a partner or a spouse of the person with dementia, the change within the intimate relationship led to: i) a significant reduction in conversation and interaction between the two people; ii) a reversal of roles if the person with dementia had previously been 'the strong one'; and iii) a change in the way social time was spent, for example, fewer or different holidays, and a discontinuing of hobbies/daily activities. The therapeutic relationship provided a 'bridging' relationship that supported the carer through the changes in their intimate relationship, and provided a space where a carer could reflect on themselves in their current position to enable self-trust and self-confidence to develop.

When a carer was an adult child of the person with dementia, the change in the relationship sometimes triggered issues and events from the past. This was in relation to: i) complexities in the parent-child relationship which had become problematic in the current situation; and ii) previous significant life events which had an impact on the current situation. Therapy helped to address issues that arose, including feelings of grief, responsibility and beliefs about oneself.

Lack of understanding/validation from others

All participants discussed the importance of having friends/others who provided understanding, empathy and validation. Whilst the benefits of this are well documented, it is perhaps particularly pertinent for this client group because part of their difficulty is the loss of what was often an intimate or close relationship with the person with dementia. For some participants in this study, the provision of what came from a spousal or parent-child relationship was needed from elsewhere. When friendships or other family relationships did not provide this, a therapeutic relationship was a significant alternative.

Poor family relationships

Poor or complex family relationships can cause minimal problems until a difficult life event takes place. A lack of support from family members was a significant theme within the information shared by participants mainly because negative feelings, such as anger, developed within carers in relation to the lack of support/contact received. Therapy enabled feelings to be discussed, and provided a space for information about available services for carers to be provided.

Talking to someone 'neutral'

Whilst sharing information with someone 'neutral' is commonly cited as a reason for talking to a therapist, this theme was particularly significant within our data. Carers found it helpful to talk to: i) someone who was not personally involved because 'a better response' would be given; ii) someone who would keep the information confidential, and not potentially share it with friends/family; iii) someone who would not be burdened by the information; and iv) someone who would not potentially think differently about the person with dementia after hearing a carer's feelings.

The caring situation

Most carers will experience the longevity of a caring situation. In our study, therapy helped to provide skills and coping strategies for the future. This was likely to have been of much importance in a caring situation, and was likely to have continued in a dynamic way once therapy was completed.

Most of the participants had competing demands on their time. Therapy was a helpful space to make sense of issues that appeared overwhelming and jumbled. Caring can require a person to review many other aspects of their life in order to be content with the time and commitment given to different parts of their life, including the role of carer.

Growth

The carers in this study described growth within difficult situations. This was of particular interest as it contrasted with much of the other data provided. Positive outcomes occurred in the following situations: i) when carers had made complex and difficult decisions; ii) when new roles were undertaken (because it was not possible for the person with dementia to fulfill roles that they had previously undertaken); iii) when carers believed that their partner would be proud of them; iv) when carers developed trust and belief in themselves; and v) when a decision had an unplanned positive outcome, for example, the benefits of changing a job role.

The therapeutic relationship

For some clinicians, the therapeutic relationship is important. For others, it is the central mechanism of change (Jacoby, 1984). For the participants in this study, a good connection with the therapist was of paramount importance. Carers needed to feel at ease and comfortable, and they listed various qualities which they felt were important within the relationship with their therapist. As is inherently the case, exploration of non-specific factors was difficult. However, the following is a summary of what participants were able to reflect:

- Trust: This was believed to be, at least partly, inherent in holding a position as therapist. Holding such a role demonstrated that the therapist was committed to doing something good and would deliver. Knowing that information would be kept confidential also helped carers to trust their therapist. Being open, understanding, friendly, and not appearing to make judgements also helped to build trust.
- Genuineness: Being consistent, open, understanding, and easy to communicate with helped to demonstrate this quality.
- Participants felt that they needed to relate to their therapist, for example by 'seeing something of themselves' in their therapist. For some participants, the age of the therapist was a relevant, if not major, factor.

- Understanding: This was one of the most significant themes for all participants. None of the participants felt that a therapist needed to have gone through a similar situation to provide understanding. Demonstrating understanding by making interpretations, remembering information between sessions, and helping carers to reflect and make plans were all ways of demonstrating understanding. Overall, this was a difficult concept to operationalise.
- Self-disclosure was a topic that was raised in both a positive and negative context by participants. Too much self-disclosure was thought to be unhelpful. However, used in the right way, self-disclosure helped to strengthen the relationship between the carer and therapist.

The ways in which carers make sense of therapy alongside the goals of clinicians

The matching of clinician and client goals is one of the many skills needed for a successful therapeutic intervention. However, the process of developing shared goals is not easy. We have attempted to map clinician goals for therapy onto client reflections of their experiences:

- All participants identified trust, genuineness, openness and understanding as essential components of therapy. In several cases, clinicians stated that they used the core conditions of person-centred therapy.
- There was a difference between the language used by clinicians when they described their goals, and the language used by clients to describe the work they had done together.
- There appeared to be variation between participants regarding the degree to which they were able to describe the aims of their therapy as stated by the therapist.
- Some clinician goals were fairly broad; however, some participants gave more specific outcomes for their therapy.

Discussion

The aim of this study was to explore the experiences of carers of people with dementia undertaking therapy, and the processes of change within therapy. Through the analysis of the data, three themes emerged: i) issues regarding therapeutic interventions pertinent to carers of people with dementia; ii) issues regarding the therapeutic relationship/non-specific factors within therapy; and iii) understanding about how carers make sense of therapy alongside the goals of clinicians.

To aid the reader, there is a table of example quotations (Table 1), which is referred to throughout the discussion section.

i) Issues regarding therapeutic interventions pertinent to carers of people with dementia

The participants in this study were spouses or adult children of people with dementia and were between 55-80 years old. They were all White British. This section of the discussion highlights the needs of carers of people with dementia and identifies how therapy can address these needs.

Changes in the relationship with the person with dementia

The onset and progression of dementia is likely to result in a change in the relationship between a spouse and their partner, or a child and their parent. In this study, the change in the relationship between spouses resulted in the loss of conversation between two people, a reduction in interpersonal connections, and a loss of activities undertaken as a couple. The increased dependence on the part of the person with dementia also meant that carers were less able to undertake activities they would once have enjoyed on their own. These findings are consistent with those in current literature (eg Sanders & Corley, 2003) which highlight the losses that occur within intimate relationships during the journey through life with dementia. What are less well documented are models of grief in dementia caregiving, and a description of detailed clinical interventions that can be used effectively with clients in this situation. Work by Noyes et al (2010) has attempted to fill this gap by proposing key components of a dementia caregiver grief model as: i) ambiguous loss, identifying that the carer loses intimate communication with the person with dementia, and no longer feels support from them; and ii) role overload, in which the carer feels a loss of freedom and a loss of engagement in personally fulfilling tasks. The data from our participants supports the grief processes identified by Noyes et al (2010), and our study adds understanding to the role that therapy plays in helping carers to adjust to these processes. Therapy appeared to provide a bridging relationship for the carer whilst they were experiencing losses within their intimate relationship, giving the carer a person who could listen to personal thoughts (Table 1, quotation 1). The change in the spousal relationship also left carers in a position where they were required to develop a sense of self that was separate from their spouse. Therapy helped them to do this by building trust and confidence in themselves, and supporting them to feel safe in a place where they felt ultimately 'on their own'.

Particularly for spouses, the change in the relationship with the person with dementia heightened the need for understanding and validation from others (Table 1, quotation 2). The spousal relationship allows an individual to feel safe and loved (Hagerty, Williams & Oe, 2002) and reduces loneliness (Vanderhorst & McLaren, 2005). The loss of this relationship has been associated with poorer wellbeing, depression and loneliness (Peters & Liefbroer, 1997). In response to the loss of an intimate relationship, some literature suggests that further dating relationships can be beneficial (Fitzpatrick, 2009). However, other literature indicates that social support from children and family members can be an important buffer following the loss (Schwarzer, 1992). Findings from a study by Vanderhorst and McLaren

(2005) suggest that the enhancement of interpersonal relationships is more likely to have a positive impact on mental health than a feeling of connectedness with the broader community. The findings from the present study suggest that the therapeutic relationship may be one way to provide a validating and supportive relationship for carers of people with dementia, a group who may well be isolated and whose caring role often makes it difficult to spend time with those in their support networks.

The female carers in this study highlighted the need for understanding and validation within their close friendships. The male participant, on the other hand, found companionship with males in itself to be adequate to meet his needs. He did, however, have a female friendship within which he found understanding of more 'in-depth' issues. Literature suggests that because females use relationships to validate their feelings of self, and talk about things that are important to them, they are more likely to seek out social support than males (Antonucci, 2001). The data from the current study suggests that males may seek similar levels of support to females, but they may do this through female friendships or therapeutic relationships. Further research into the ways in which older males seek understanding and validation would be useful to provide further knowledge about the role of therapy for this client group.

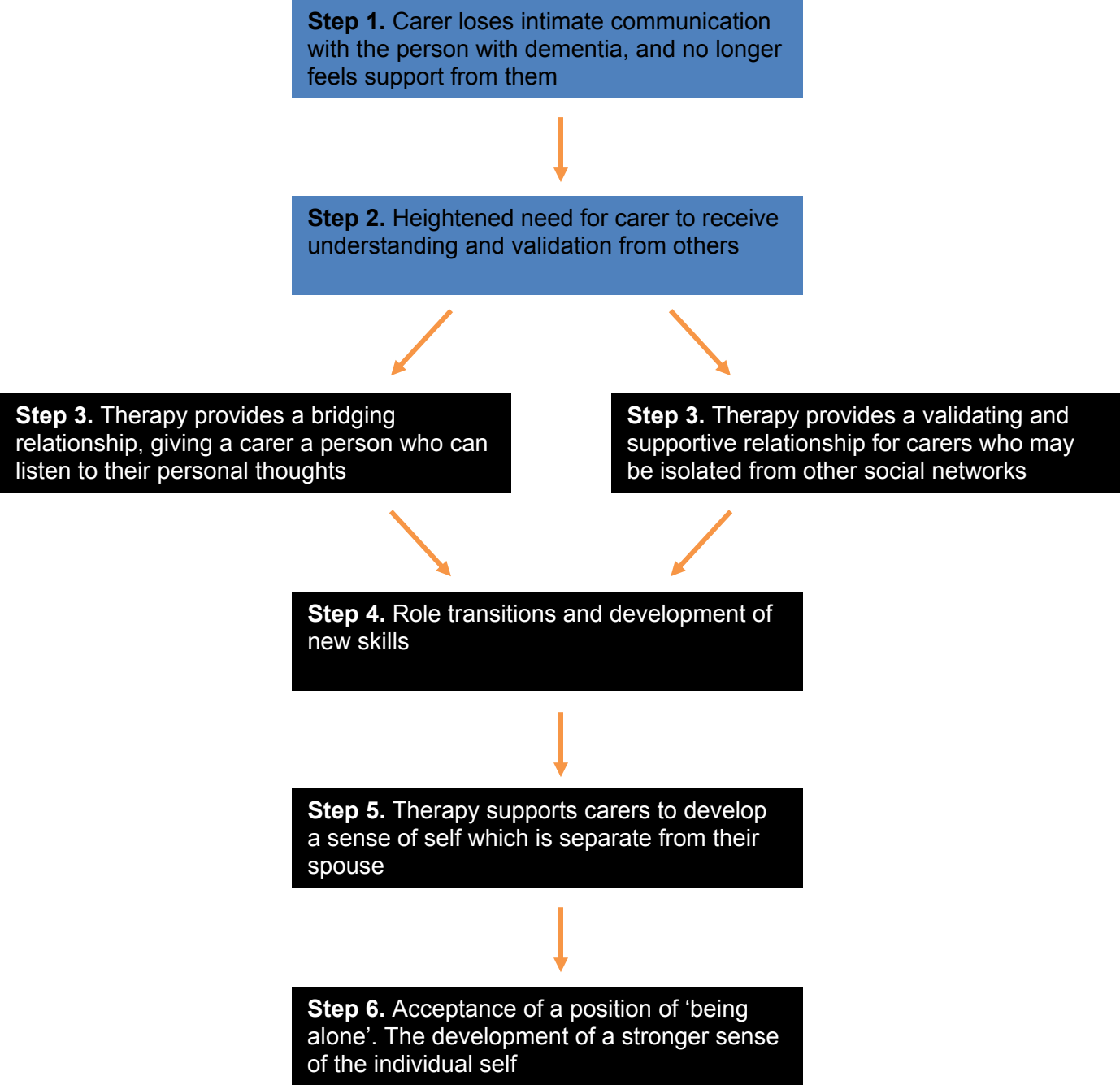
Growth

Juxtaposed, or perhaps intertwined, with the findings discussed above, are the findings from this study which suggest an amount of personal growth within what is often viewed as a stressful or declining situation. The participants in this study appeared to demonstrate growth in: i) their ability to make difficult decisions; ii) their ability to take on new roles; iii) the level of trust and belief in themselves; and iv) the relationship with the person with dementia because they believed the person would be proud of them. Recent years have seen the development of terms such as post-traumatic growth, stress-related growth, benefit finding, and thriving. These terms are often used synonymously to describe positive psychological adjustment and personal growth following a traumatic experience, and the terms imply an enhancement of previous psychosocial functioning. To the best of our knowledge, there is no specific literature examining these processes within carers of people with dementia, but there are several things from the study data that can be reflected upon. Firstly, the growth seen within our study data is not enough to suggest that a carer's level of psychosocial functioning is better than before the person with dementia received their diagnosis. However, we suggest that the processes of growth within this population have clinical relevance and are sufficient to warrant discussion. Secondly, whilst in the present study social support appears to play a part in a carer's growth, our data also suggests that growth occurs in carers due to an apparent realisation that they are ultimately 'on their own'. Within our sample, changes in the intimate relationship with the person with dementia resulted in role transitions, the development of new skills, and a growth towards an accepting position of 'being alone'. Our study participants were carers who were dealing with a continually changing intimate relationship and a potentially drawn-out grief process within that intimate relationship. This may have led to a changing sense of self in relation to the other, thus resulting in growth borne from the development of a stronger sense of the individual self.

In summary, stress-related growth within carers of people with dementia is an area that needs much exploration. The current data suggests that therapy can help by building trust and confidence in a person, helping them to acknowledge their loss, and enabling them to develop their sense of individual self in a positive way.

We have summarised the findings from the 'changes in the relationship with the person with dementia' and 'growth' sections within a model of 'change, adaptation and growth' (figure 1).

Figure 1. Model of 'change, adaptation and growth'



The dynamic and longevity of the caring situation

Carers are likely to be in a caring situation for a number of years. Therapy for this client group should therefore pay particular attention to the changing nature, and potential longevity, of a carer's problems by focusing on developing strategies that can be used over time (Table 1, quotation 3).

Characteristics that may make people vulnerable within the caring role

The following themes emerged from the carers in this study: i) a strong feeling of responsibility for others; ii) a lack of support from family members; iii) the carer being the person who 'everyone brought their problems to'; iv) a sense of satisfaction from supporting others; v) not easily asking for support; and vi) seeing others' needs as more important than their own. Whilst it is not possible to draw firm conclusions from this small dataset, it is hypothesised that some carers may find themselves vulnerable within the caring role because they hold the above characteristics, making them a target client group for psychological support (Table 1, quotations 4 and 5).

The characteristics listed above may lead to carers experiencing shame or guilt around their feelings, particularly as they may be reluctant to share feelings with family or friends for fear of influencing them negatively. The work of Gilbert (1989), amongst others, highlights that humans need to feel acceptance by others and a sense of belonging. From this standpoint, how safe a person feels is dependent on how they believe they live in the minds of others (Gilbert, 2010). Compassion-focused therapy aims to unpack experiences to try to understand the ways in which shame influences people's feelings and behaviours. We are unaware of any specific literature on the use of compassion-focused therapy with carers of people with dementia; it would be useful to further explore the use of this approach if guilt plays a significant role in (at least some) formulations of the difficulties experienced by this client group.

Transition into full-time care

It is worth noting that two participants in this study were undertaking therapy when their spouse or parent had moved into a full-time care environment. Earlier studies tended to view institutionalisation as a transition where family caregiving came to an end. However, the present study supports more recent findings which suggest the involvement that carers continue to have with their relative in a care setting can provide a continuing stress on a carer's mental health (Gaugler, Roth, Haley & Mittelman, 2008). The study by Gaugler et al (2008) examined the impact of a multicomponent intervention on carers during the transition of a person with dementia to a care setting. The intervention contained a significant counselling component, and found that those in the treatment group had fewer symptoms of depression before and during the time of nursing home admission than those in the control group. Although our study had a small sample size, it lends some weight to more robust findings that therapy can be valuable during the transition period. Furthermore, Gaugler et al (2008) highlighted that the impact of therapy on depression is of paramount importance given the demonstrated associations between depression and outcomes such as health service utilisation and mortality. Given this, the present study perhaps adds further evidence to suggest that depressive symptoms should be a key outcome measure of therapy interventions within NHS services.

Service issues

One service issue raised by carers within the present study was regarding knowledge of services and the ability to gain access to them. Carers do not always find it easy to ask for help; advertisement of availability of services (rather than having to ask their GP) was therefore important in them gaining access.

A further reflection which may be of use to service providers is that the results from the present study highlight the impact of various therapeutic approaches aside from CBT. The last 20 years have seen the emergence of an evidence base for CBT, which is in many ways superior to that of other theoretical approaches. Within the dementia care literature, much of the outcome evidence for psychological interventions for carers is following CBT interventions (eg Elvish et al, 2012), and some argue that CBT interventions are more effective than other theoretical approaches (eg Gallagher-Thompson & Coon, 2007). However, others suggest that CBT is not more favourable when compared with other approaches (Wilson et al, 2008), and it can be argued that efficacy is often demonstrated because an approach is researched, rather than because it is more effective *per se* (Hubble, Duncan & Miller, 1999). The clinicians who took part in the present study described their work as drawing from a variety of approaches, including humanistic, integrative, person-centred, non-directive, personal construct, and acceptance and commitment. CBT was used as a component of the work undertaken by the two clinical psychologists in the study; one used schema therapy and CBT alongside personal construct therapy, the other used CBT alongside a psychoeducational approach with elements of acceptance and commitment therapy. In summary, it is probably fair to say that this study lends some weight to the use of a range of therapies with carers of people with dementia. It is worth highlighting the point that 15% of outcome variance is accounted for by model and technique (Assay & Lambert, 1999; Lambert, 1992; Miller, Duncan & Hubble, 1997). Whilst not undermining the importance of a theoretical approach that 'fits' the client, much of the focus should also be on other aspects of therapy when thinking about processes of change, as discussed later in this report.

It is hoped that data from this study lends weight to the argument that therapeutic interventions (regardless of theoretical underpinning) fill a unique need for carers of people with dementia.

ii) Issues regarding the therapeutic relationship/non-specific factors within therapy

As within previous literature, non-specific factors within therapy were of significant importance within our data (Jacoby, 1984). Understanding, trust and genuineness were all factors that participants felt were vital for successful engagement in therapy (Table 1, quotation 6).

The issue of self-disclosure was raised by some of the participants in this study. One participant gave an example of a previous therapist who had crossed too many boundaries and appeared to be benefiting from the relationship herself. However, another participant seemed to hold the view that self-disclosure had strengthened the therapeutic relationship (Table 1, quotation 7). Self-disclosure is an interesting topic, which raises professional and ethical issues. It is an area within practice on which professionals hold a range of views, but it is rarely discussed. In an insightful and courageous paper, Speight (2012) discusses many of the issues around therapeutic boundaries and self-disclosure. She reminds us that boundaries are crucial in defining a therapeutic frame, in promoting client welfare (Borys, 1994), and in ensuring that the client's agenda is central (Simon, 1992). Speight (2012) states that the commonly held view is that therapists are cautioned against crossing boundaries ultimately to prevent client harm, exploitation, and sexual misconduct (Gutheil & Gabbard, 1993). 'Rarely are boundary crossings discussed as beneficial, therapeutic, or positive events within therapeutic relationships.' (Speight, 2012, p. 137)

Despite this, there are arguments within the literature which express a less conservative view of boundaries. Lazarus (1994) argues that the universal notion of boundaries can lead to inhumane, sterile and artificial relationships. Glass (2003) suggests that boundary crossing can facilitate the development of the therapeutic alliance. Consistent with the findings of the present study, Gelso (2005) argues that genuineness and openness are the key features of a 'real' relationship, suggesting that close boundaries can foster the interaction between two 'real' people even within the professional relationship. Indeed, congruent with some of the participants in the current study, Speight (2012) cites an example of a client who looked for the 'real' person behind the mental health professional.

It is also interesting to reflect on client assumptions that their therapist is not in the same situation as them. When people are in a distressing or difficult situation they often feel (for some time at least) that no one else is going through a similar situation. Whilst the current results suggest that participants did not think that their clinician needed to be in a similar situation for them to feel understood, the data also implies assumptions that may impact on the therapeutic relationship.

In conclusion, we suggest that 'one size does not fit all'. The data underline the complexity of the issues that arise around self-disclosure. At the very least, clinicians working with carers of people with dementia should think carefully about the role of self-disclosure, and use supervision to discuss issues as they arise.

iii) The ways in which carers make sense of therapy alongside the goals of clinicians

A shared understanding between a client and clinician of what is happening within the therapeutic space is of paramount importance. The findings of this study suggested that:

1. Clients and clinicians may use different language to describe processes and goals. This is a reminder to practitioners to listen to the language of their clients, and to continually assess whether the client's goals are directing the therapy; and
2. Whilst it is not always easy to explicitly agree therapeutic goals between a client and clinician, this should be strived for

Limitations and considerations for future research

Due to difficulties with recruitment, the sample size for this study was small. However, the richness of the data provides insight into client experiences and processes of change, which are important for the development of clinical practice. As discussed in the methods section, potential reasons for recruitment difficulties included fewer carers receiving therapy than anticipated, and refusal of carers to take part. Our overall sense is that a larger study undertaken over a longer period would facilitate recruitment for future studies.

Participants were drawn from across the North West but it is acknowledged that this is a specific geographical area. Replication of this study in other areas would help to develop the data.

The results from this qualitative study provide a useful grounding for future studies that may be able to use both quantitative and qualitative methods.

Conclusions

This study provides insight into client experiences of therapy and the processes of change within therapeutic interventions. For carers of people with dementia, there are clearly many facets within the therapeutic space that address their needs on various levels. This study offers valuable insight into how therapy addresses issues specific to this client population, whilst also highlighting the similarities with other client groups. It is hoped that the work will inform clinical practice and development of further research. The following points are a final summary of our key findings and recommendations:

- Changes in parts of the relationship between a person with dementia and their relative can result in losses of intimate communication and support. However, alongside this, processes of growth can emerge. The therapeutic relationship can be valuable in supporting processes of loss and growth.
- The therapeutic relationship can provide: i) a 'substitute' for the changed parts of a relationship between a person with dementia and their relative; ii) a space for validation and support; and iii) a place in which a carer can develop a more independent 'sense of self'.
- Understanding, trust and genuineness are important for building successful client-clinician relationships.
- Clinicians should carefully consider the arguments within the literature on the issue of self-disclosure. Supervision should be used to reflect on this.
- Data from the current study lends weight to the use of a range of therapies with carers of people with dementia. The therapeutic relationship and the use of formulation enable therapeutic interventions to fill a need for carers of people with dementia, which may not be met by other support services.
- Clinicians may find it useful to explore literature in the area of stress-related growth when working with carers of people with dementia.
- Clinicians should be aware of certain characteristics that may make people vulnerable within the caring role. These characteristics include people who: i) have a strong sense of responsibility for others; ii) gain satisfaction from supporting others; and iii) see others' needs as more important than their own.
- Clinicians may find compassion-focused therapy helpful if there are elements of shame/guilt within feelings expressed by carers.
- Therapy can be a valuable place for support for a carer if a person with dementia is moving into a care setting.
- Carers do not always find it easy to ask for help; advertisement of availability of services is important in order to improve access to counselling/psychotherapy.

Table 1: Example quotations

1	'I just sit and chat. Yeah, I do. Yeah, we just hold a conversation. But it's nice to hold a conversation with someone, right. Because I can't have a conversation with [Tom].'
2	'Yes, there is a lady I've got friendly with, she walks her dogs, so I've become friendly with her, and she's a widow. So we understand.'
3	'But I'm so glad that I did get the counselling because it's made this bit easier now. I feel that I'm coping with what's happening now better than I would have done had I not spoken to somebody, because I think the next few months are going to be very difficult, because Dad is deteriorating.'
4	'I think it's almost like feeling a bit of a failure. I always said I was a coper, but I'm not as much of a coper as I thought I was.'
5	'And he's helping me to focus on me, which is something people don't do. So he's helping me focus on me, and trying to help me, myself, rather than what I normally do, helping other people.'
6	'Whoever I meet I've got to trust them. If I don't trust them I tend not to say much and keep very quiet... [my therapist is] very honest, he's very open, he understands me. I think it's trust more than anything, he's very open, he's friendly. I think we've got a good connection.'
7	'We just chatted generally about how she's got a grandchild and I've got one on the way.'
8	'I think if the situation was like this and [Albert] was fit and well, the marriage wouldn't last, but the marriage has got to last now, you see what I mean, because the situation is because [Albert] isn't well. Now, it's got to survive now, because I love [Albert] and I'm there for him.'

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Appendix 1: Semi-structured interview guide

1. Please describe your experience of current activities in your everyday life.

What does a typical week look like?

Please describe any recent (in the last year) changes in your everyday life activities.

Do you find any of these changes particularly worrying?

What do you do when you feel guilty/sad/frustrated?

2. Please describe your social relationships with your spouse, family and friends.

What do you most appreciate?

Is there anything that you miss?

Is there anything that worries you?

What importance does dementia have within the issues that you are talking about?

3. What were your expectations of therapy?

4. On a scale of 0-10, how helpful is/was your therapist/counsellor?

What puts them at that number?

5. If you went home today and a friend/relation asked you about your therapy sessions, how would you describe what happened?

6. Please can you tell me a little bit about your experiences of therapy up to now.

What does seeing a 'trained' person mean?

Are the sessions planned at all in advance? Are you involved in the planning?

Is the relationship with your therapist important? What makes a good/successful relationship?

7. Can you tell me about the things that have happened during your sessions that have been helpful?

8. Have there been any things during your therapy sessions that were not done well, that were missed, or that could have been done better?

9. Have the between-session suggestions been helpful?

Which ones specifically? And how so?

10. How were the practical arrangements of the sessions for you (for example, location)?

11. Please can you tell me about the impact that your therapy sessions have had on your own life and the lives of your loved ones.

How will you know it has been worthwhile attending therapy sessions?

What has changed for you or what will have changed for you ideally?

12. Would you recommend that a friend/relative go for therapy sessions if they felt that some sessions would be helpful?

13. Is there anything else that you would like to discuss that we have not talked about?

Appendix 2: Clinician questionnaire

Please answer the following two questions in relation to your client who is participating in this study.

1. Please describe the theory/approach which is informing your current work with this client.

2. Please outline the main goals/outcomes for therapy from your perspective.

Thank you for taking the time to complete this questionnaire.