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Delivering effective counselling for people with dementia and their families: Opportunities and challenges

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Abstract

This article explores the prospect of delivering counselling to people affected by dementia from the perspective of persons responsible for delivering an integrated dementia support service, emphasising an underpinning relational approach. Findings originate from interviews with an experienced counsellor, the counselling service co-ordinator and people affected by dementia. Framework analysis was adopted to generate themes related to the study aims. Effective counselling delivery is reliant on the counsellor's practice philosophy and appreciation of the lived experience of dementia from a person-centred understanding. Participants discussed the benefits to offering a holistically understanding service, supportive of the needs of people affected by dementia, and how this can affect access or uptake of counselling. Findings demonstrated that counselling is a worthwhile and effective intervention to offer to people living with dementia and family caregivers. A number of recommendations for adjusting the scope of relationship-based counselling to promote effective delivery have been made.

KEYWORDS

cognitive impairment, counselling, dementia, psychosocial interventions, relational counselling, therapeutic relationship

1 | BACKGROUND

1.1 | Dementia as an area of opportunity

Dementia affects 46 million people worldwide, which equates to around 7% of the population over 60 years old (Prince et al., 2016). As the condition progresses, aspects of daily life can become more difficult and people living with dementia often require support from family members and healthcare professionals. As there is currently no cure for dementia, non-pharmacological treatments and areas of

support are imperative in maintaining the quality of life of people living with the condition. These treatments are beneficial and may be cost-effective (Olazarán et al., 2010). Certain types of dementia, most commonly Alzheimer's disease and fronto-temporal dementia, are associated with problems with emotional regulation, although the individual does not always notice this themselves (Goodkind et al., 2010). Many people with a broad range of dementia diagnoses experience anxiety and depression (Orgeta et al., 2014), and identifying and treating these symptoms should be included as an integral component of any post-diagnostic support for people with dementia

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(Salzman et al., 2008). Furthermore, occurrence varies between individuals and with disease progression; depression is more common in people with mild-to-moderate dementia, whilst anxiety is more frequently observed in those with advanced dementia (Lopez et al., 2003). However, this is often due to difficulties in expressing and communicating unmet needs (Cohen-Mansfield et al., 2015). This suggests the potential for interventions to support people living with dementia in expressing their emotional needs. Counselling is one such established therapeutic intervention, which may be beneficial in this regard.

1.2 | Common factors in counselling approaches

Counselling is a form of talking therapy, which offers support to people in many areas of their lives, including relationships and family, across the entire lifespan (Young & Valach, 2016). Recent research has indicated that there are over 500 different identified approaches within the diverse field of established talking therapies (Prochaska & Norcross, 2018), yet the practice of what is described as counselling within the UK context largely operates within a set of humanistic practice principles closely associated with the work of Rogers (1902–1987). These principles state that people are more than the sum of their parts and cannot be reduced to components. Humanistic psychology posits that people have goals and an awareness of the future, and seek meaning, value and creativity (Moss, 2001). Human beings, through a Rogerian lens, are constantly responding to both the internal and external environment and experiences, which negatively impact the potential to thrive and to grow towards one's goals or full potential (Rogers, 1959).

Drawing from these principles, Rogers (1959) offered his hypothesis of six core conditions necessary to facilitate therapeutic process, with empathy, congruence and unconditional positive regard identified as key counsellor attitudes required to foster therapeutic shift. This is where a client has a significant and meaningful change in outcomes (such as feelings of depression or anxiety) as a result of counselling. Current research and meta-studies (Cooper, 2008; Lambert et al., 2004) reflect that there is no clear evidence that any approach is superior, but the relationship between the counsellor and client is the most important determinant of successful outcome in counselling beyond any model of therapy, techniques or interventions (Orlinsky et al., 1994, 2004; Paul and Haugh, 2008). Counselling within the Rogerian tradition involves placing the client's understanding of their individual experience as the focus of the work.

1.3 | Importance of therapeutic relationship

An established therapeutic relationship allows the therapist and client to work together towards the aim of achieving the client's set goals (Carey et al., 2015), and can be expressed in many ways, that is verbally and non-verbally (Paul & Charura, 2015). Parallels can be

Implications for practice

- Counselling for clients affected by dementia should focus on principles of person-centred practice, supporting remaining abilities of people with dementia and nurturing existing relationships.
- Practitioners should recognise the impact of loss of abilities and sense of self for people with dementia, supporting them to develop coping mechanisms and reduce loneliness, and promote inclusion.
- Providing interventions within a dementia-friendly environment may offer continued support, and lessen the impact of practical barriers associated with living with dementia or providing full-time care for a relative.

Implications for policy

- There is a need for policymakers to identify a core set of strategies and modifications required to effectively develop and maintain a therapeutic relationship, and deliver counselling interventions for people with dementia.

drawn between the therapeutic counselling relationship and the concept of relationship-centred care in dementia (Nolan et al., 2004), which emphasises the value of quality relationships to lead to positive change in care encounters. It offers a basis for nurturing interpersonal relationships with people with dementia: the 'senses framework' (Nolan et al., 2006), giving emphasis to feelings of security and belonging, continuity, purpose, significance and achievement in caring relationships. The sense of achievement resonates with goal attainment in counselling interventions. The counselling practitioner's role involves 'empathic, affirmative, collaborative and self-congruent engagement' (Orlinsky et al., 1994), which therefore should be seen as an equal recipient of feelings such as purpose and significance in therapeutic exchanges. However, in a field where the development and maintenance of a therapeutic relationship is increasingly suggested as a prerequisite for successful therapy (Paul & Haugh, 2008), this raises valid questions surrounding best practice approaches to forming impactful therapeutic relationships with people affected by dementia.

1.4 | Challenges of counselling for dementia

To date, there is very little evidence around the effectiveness of counselling for people with dementia or guidance to support therapists delivering this. Additionally, very little is known about how best to deliver counselling to this population who are likely to have additional challenges with their memory, language, attention, judgement, and capacity for planning (Arvanitakis &

Bennett, 2019). These conditions are likely to affect the extent to which individuals can engage with counselling, as an ongoing verbal dialogue is critical for the counselling process (Young & Valach, 2016).

A recent systematic review (Shoesmith et al., 2020) identified a total of 16 studies involving people with dementia who received a counselling or psychotherapy-based intervention, and 15 aimed at informal caregivers. For interventions aimed at people with dementia, cognitive behavioural therapy or problem-solving approaches were most commonly used. Psychodynamic approaches appear to be untested with this population (Shoesmith et al., 2020). Counselling has shown improved problem-solving (Carpenter et al., 2003) and reductions in depressive symptoms (Scholey & Woods, 2003) for people living with dementia. For interventions that delivered counselling or psychotherapy to people with dementia and their families (with some attending all sessions as a dyad, and others offering combinations of individual and dyadic counselling), improvements have been found in quality of life and reduction in family conflict (Fauth et al., 2019) and reduced suicidal ideation (Kiosses et al., 2017). However, there are also several studies that reported no change in outcomes including depression and quality of life (Waldorff et al., 2012) and cognitive function (Burns et al., 2005).

The reviewers identified more compelling evidence to support counselling for informal caregivers, demonstrating universal benefits for coping abilities across a range of different approaches. For people with dementia, the evidence to date is mixed, and modifications to interventions are frequently required. This may include simplifying materials, reducing content volume or involving the person's family members to support their participation (Spector et al., 2015; Tay et al., 2019). To date, no standardised form of counselling or psychotherapy has been developed for people with dementia.

The current study aimed to explore the potential for providing counselling to people with dementia and their relatives through a specialised counselling service, underpinned by a relational therapeutic approach.

2 | METHODS

This article reports on data gathered from the service co-ordinator and counselling practitioner for a counselling service delivered within a third-sector organisation, and interviews with people accessing the service. Each individual client took part in an in-depth semi-structured interview at the end of the project, drawing on their experiences of delivering the service. Interviews were audio-recorded and transcribed by the first author, with any identifying information removed during transcription. Pseudonyms were used for presentation purposes.

Prior to data collection, ethical approval was obtained from the Leeds Beckett University research ethics committee. Participants provided written informed consent prior to interview.

2.1 | Intervention and providing organisation

The counselling intervention ran for 18 months within a faith-based community organisation in England, staffed by one counsellor offering a course of 12 weekly counselling sessions lasting one hour. Counselling recipients were either living with a diagnosis of dementia or providing care for a relative with dementia, and were referred to the service through members of the NHS or third-sector agencies. The service was provided as part of a funded project to establish a range of supportive provisions for people affected by dementia in the local community. This project aimed to improve the well-being of people living with dementia and their relatives, and offered a weekly programme of meaningful activities for dementia such as reminiscence, peer-led support for informal carers and practical assistance (e.g. with finances or housing). All activities were funded through the project and free to access.

2.2 | Participants

The therapist and service co-ordinator were female and identified as White British. Thirty-one clients participated in pre- and post-counselling interviews: 29 took part before they began counselling, and 25 were interviewed after their final session. Six client participants were living with dementia; the other 23 supported someone with dementia. Participants were mainly female ($n = 24$) and identified as White (British, Irish or other, $n = 30$). Concurrent interview data from individuals with dementia and family carers reflecting on their experiences of the intervention and its impacts are reported in Griffiths et al. (2020).

2.3 | Data analysis

Framework analysis (Smith & Firth, 2011) was conducted by three authors (CS, AWG and ES). Initial coding was used with a selection of the full data set to identify core themes and develop a coding framework. This framework was used to guide further data analysis. Subsequently, the authors discussed their analysis and reached agreement on where quotes should be placed within the framework.

3 | RESULTS

Analysis of participant interviews resulted in three overarching themes elucidating the maintenance of a therapeutic relationship between the counsellor and her clients. These related to the attributes of the practitioner, the expectations of both provider and recipient of the therapeutic intervention, and the environmental and interpersonal factors of the service provision. The data presented in this manuscript originate from interviews with Patricia, the counsellor delivering the therapeutic intervention, Megan, the service co-ordinator overseeing

the provision of counselling and the wider project within the lead organisation, and participants who had received the intervention.

3.1 | Uniqueness of the counsellor

Direct discussion with the counselling practitioner revealed some personal attributes which shaped the course of the intervention and provided the basis for relationship building with clients.

3.1.1 | Practice philosophy

Central to the counsellor's philosophy to delivering therapy was the underpinning relational approach, applying this to both people living with dementia and their family members in counselling. This consists of modalities that throw light on a different dynamic of interpersonal relationships. There is a focus on the therapeutic relationship, and the key principles of this approach consist of the following:

1. Relations between people are the basis of social and individual life, and relational concepts are used to understand human life in all its complexity.
2. Relationships are of fundamental importance in:
 - a. The development of personality and a sense of self
 - b. The difficulties clients bring to therapy (relations with the self and relations with other people)
 - c. The therapeutic process (the therapy relationship is the heart of the process)

The relational approach is therefore perhaps best considered as a framework that is considered central to virtually all approaches (Finlay, 2016; Paul & Charura, 2015).

Patricia reflected on the versatility of this approach for a variety of groups, and affording her flexibility to combine the approach with other models based on intuitive expertise:

I work with people in the room, whatever's in the room. So I do work relationally. But... there might be times that it's definitely client-led, there might be times there's a bit of TA [transactional analysis] in there, it really just depends on that client.

(Patricia, counsellor)

In addition to an inductive approach of reacting to the individual client's needs, the counsellor identified her own impact on the therapeutic relationship and how she could manage the course of a counselling session. Her perspective is commensurate with the aims of the relational approach, identifying the client's personal impact on the counselling experience.

Her active role in this relationship required her to thoughtfully contribute to the therapeutic process with each individual and respond to the client's needs:

The sessions are very much about me, and how I see that person and how I see our relationship. So, there might be some times that you do have to be more challenging there might be sometimes you just sit back and... and let the client lead, it just really depends and I think... I'm really not being big headed about it I do think it's about ... me as a person in that room.

(Patricia, counsellor)

Use of the relational paradigm may have formed a basis for the counsellor's appreciation for non-verbal communication, essential to communicating with those with dementia. She utilised body language and other reflections of a person's state of mind to support effective communication with clients. This highlights the value placed on empathic understanding, indicating that a relational approach may be one way to establish and build a relationship with counselling clients affected by dementia who demonstrate some impairments in communicating their thoughts and emotions.

3.1.2 | Client-influenced understanding

The counsellor highlighted the extent to which her perspective was shaped by working with people affected by dementia in her everyday practice, in particular the need to accept the progressive nature of dementia for her clients. She pointed towards an empathic understanding of the condition, and a greater appreciation for some of the core concepts of her counselling practice, which had developed over time.

This continued throughout the current intervention, with each client presenting opportunities to develop and shape future practice:

I think she's learned quite a lot from me, to be honest as well, I think she's taken some things from me that maybe she's been able to use in her work because you know she'll say "well I might know another client who's done this", so I think she's picked up a few things from me in terms of... how to approach things with maybe some of the other people that she counsels on a regular basis.

(Natasha, spouse caregiver)

The counsellor also highlighted how her style of communicating with clients more generally was affected by observing the differences in relating to people with a diagnosis of dementia:

I feel like I understand the word acceptance and, know the implications of that, way more than I did three years ago ... maybe it is accepting but it's just the way that you see people... processing things differently has really, changed how I work because you're just open

to- to anything, just the way people are, and how they process...

(Patricia, counsellor)

Something that had a clear emotional impact on the counsellor was the expectation that clients with memory recall difficulties may be unable to remember the work they had shared. The counsellor felt accustomed to clients recognising her and acknowledging the significance of their relationship, and this feedback may have been an important part of her self-reflection as a practitioner:

P: ...we had fantastic sessions it was really good. And now she's in the centre and she doesn't know who I am.

Interviewer: That must be tough for you.

P: It's really tough on me yeah. So... she'll say hello dear like she says hello dear to everybody, but she doesn't know who I am.

(Patricia, counsellor)

She described having found this situation difficult to overcome, perhaps because this encounter gave her no opportunity to interpret after the end of the intervention whether she had influenced a meaningful, positive change. She instead chose to accept the inevitability of the situation and reflect on the immediate impact of the counselling intervention in the light of these difficulties.

I struggle with... these people aren't gonna get better, I struggle with all that, but... I think, you know that's part of your job really and that's part of, what I'm doing but I also, I'm really proud of what I've done, erm... and I'm feel like it has helped a lot of people.

(Patricia, counsellor)

This perspective will be explored in greater detail under the second theme presented below, 'expectations of practice', relative to the potential benefits of counselling for people living with dementia and family members coping with their caring responsibilities.

3.2 | Expectations of practice

Discussions took place with the participating counsellor and service co-ordinator reflecting the challenges to delivering counselling to people living with dementia and their relatives. There is a clear therapeutic potential of counselling for people with dementia. This theme outlines the expectations held by counselling stakeholders and clients in terms of the attitudes and abilities facilitating efficacious counselling practice.

3.2.1 | Nature of relationships

Central to the concept of engagement in counselling was the ability to engage in a relationship with the counsellor. Many of the individuals offering their reflections on counselling in this study highlighted the scant opportunities they had for sharing and relating to others.

I don't particularly want to be in a group with 277337181 other people with Alzheimer's. I don't think that would be very positive ... and as I say other people don't want to hear me talking about it all the time.

(Grace, person with dementia)

This reflects the importance of identifying whether people living with dementia have the social capital to permit open exploration of their emotions and experiences, and striving to put these in place where necessary. The counsellor emphasised that many of her clients with dementia were accustomed to feeling like a 'burden' for receiving care from relatives, and concealed emotional support needs from them to avoid placing additional pressure on them.

...whilst they can still have thoughts and process things, they don't wanna be telling their loved ones how they're feeling. Because they don't wanna scare them either.

(Patricia, counsellor)

In line with a relational approach, the counsellor placed the relationship at the core of therapy. This view was shared by her clients, some of whom attributed their relationship as the catalyst for engaging more openly with therapy:

[I was surprised by] just how easy it was to talk. I didn't think I'd be as open as I have been. Cos I were keeping things to myself a lot ... but I'm sort of more open since I've been talking to Pat about things.

(Terry, spouse caregiver)

The importance of this relationship was magnified by the difficulties faced when clients were unable to retain fundamental memories during the intervention:

so there's people that come in, and you know that they're not gonna remember you next week. So, whatever we've worked and talked about... they're not gonna remember and we can't continue on our journey.

(Patricia, counsellor)

Once therapy ends, a person living with dementia may eventually be unable to recall that they received counselling. This was not considered a barrier to entering into the intervention, providing that the client could engage to a sufficient degree throughout sessions. The

counsellor, supported by the service co-ordinator, would consider the therapeutic potential of counselling where necessary and signposted families to alternative activities if counselling was deemed inappropriate; judged individually on the basis of a person's capacity to engage with counselling.

This emphasises the importance of determining willingness to engage in therapy, as well as an understanding of the core concepts explored during sessions, for clients experiencing difficulties with cognition or memory. One such key concept for therapy in this client group was the exploration of acceptance, which is discussed in the next section of this theme.

3.2.2 | Client attitudes towards counselling

Participants described common misconceptions around counselling and internalised stigma that emerges when someone recommends counselling to others:

There is a lot of stigma and people ... I've told, I've said oh you should go... "oh I don't need counselling!" they do, but they just don't think that they need it. I think that they would get a lot from it but that word... counselling, conjures up lots of not so good things really... and it's not, for me it's been an opportunity to talk and reinforce some of the things that I already knew.

(Natasha, spouse caregiver)

Negative perceptions of counselling may originate from commonly held misconceptions, but some may have previous bad experiences, which shape their attitude towards future counselling interventions:

[My past experience] wasn't very good in fact I ended the sessions before the six. So I suppose I did have preconceived ideas of how it would be, which were all wrong, cos I have to say this has been great it really has been very helpful ... when I've had counselling previously, it's been the situation where we've just sat and looked at each other and you're waiting for somebody to say something, and I've really struggled to talk and that was really uncomfortable.

(Jane, spouse caregiver)

Family carers may be reluctant to admit to needing help with coping with their caring responsibilities. They may feel that devoting time to self-help activities such as counselling may detract from the time they devote to their relative. Additionally, competence in the carer role may be connected to a sense of pride, something that may be threatened by asking for or accepting help from other people.

Doctors told me to go. [Local carers support service] ... was pushing me. Social workers ... they were pushing

me to it and at first I was like no I don't need it ... But, eventually came round to the idea ... I just thought it was a waste of time to be quite honest. But now I think I probably do. ... yeah, because the psychiatrist at the hospital kept having a word with me and you need some counselling or something like that. And I said no. I'll be alright I'll get through it. ... Always thought it's a waste of time. That's my opinion. Might not be, I might have a different opinion when I've talked to somebody.

(William, spouse caregiver)

Informal carers may internalise feelings of guilt due to the negative feelings they developed around their caring role. Such feelings may be difficult to admit to, and create a barrier to accepting support from others to cope.

Now the carers have the same sort of things, but in a different way cos it's not them ... "I'm worried and I'm scared what's gonna happen to say my husband... I'm worried I won't be able to cope with it... I feel resentful, why is it us... why do I have to look after him, I feel guilty that I feel like that. How can we address the here and now? How can I accept that my husband or my wife's never gonna be my husband or wife again? How can I accept the change in the relationship?"

(Megan, Service co-ordinator)

These feelings may be managed by clients accepting the need to be open and honest with the counsellor in order to get to the root of their problems in counselling.

cos I've been... the first couple of sessions, I talked to- I spoke, erm truthfully and honestly about the situation that I was in and the situation my husband's in the situation we're both in together. Erm... which isn't the best by any means, but... you know, erm... but talking to someone, that listens and understands is... far better than not talking.

(Lorraine, spouse caregiver)

3.2.3 | Emphasising the present

Previous work with this client group has explored the role of counselling in facilitating acceptance of their situations (Griffiths et al., 2020), a process which the counsellor described as a pivotal step towards coping with the impact of dementia. In her interview, she suggested that the prospect of accepting a trajectory towards declining health and end of life was a difficult subject to address with her clients.

we're all gonna die... something's gonna happen to, everyone... but they know how it's gonna happen or

they've got a really good idea of how it's going to happen, which is scary, cos will they end up in a home you know what will happen? And it's very difficult because I'm sat there and I don't know what's gonna happen.

(Patricia, counsellor)

The counsellor expressed a feeling of helplessness as she could not give definitive answers about what might happen in the future. To counteract these feelings, she instead turned her attention to emphasising the presence in the 'here and now' and valuing the present day. The participants echoed this feeling of uncertainty, acknowledging that negative feelings towards the future could appear at times.

Hmm... sometimes I think... when I'm tired I suppose, I've lived long enough I don't want to go on anymore. Cos you do have to struggle a bit more. Cos things are more difficult. Erm... but that doesn't happen very often. So... I'm looking forward to Christmas we'll have a lovely time together ... I'm going along alright just now. I think if anything happened then that might be different.

(Grace, person with dementia)

The counsellor recognised that the benefits of her work with this person may not have carried forward as time passed and her health declined, but she placed value on transforming the client's perspective in that moment. In this way, both client and counsellor learned to appreciate the benefits of counselling in the present moment, thinking less about the future implications.

I mean I know I've still got the nasty bit at the end, but until then you know you can, sort of see things... you don't look too far ahead and do what you can now ... Well certainly for this- this er, phase of it it's helped, on the other hand I'm always aware of what's going to come in the future cos it can take quite long it's already taken two years, and it's only relatively minor things ... you've got to take it as it comes and keep going for as long as you can.

(Bill, person with dementia)

An essential aspect of the approach to working with people affected by dementia for the counsellor was the need to 'let go' of her desire to focus on repairing the client's situation in terms of living with the disease and its resultant impact on their future. Patricia discussed her ways of working to encourage clients to accept their situation, with the understanding that she must also follow a path to accepting the nature and progression of dementia:

I'm never gonna be able to fix those people. I'm never gonna make them better. But my aim is to make things better for them in the way that they're living to be able to try and understand, to take away, some of

the scaredness somehow to sort of understand what they're going through ... we've got twelve weeks and we know that's the ending. And at least they're getting something, but that's a sad bit for me as well because I haven't fixed the problem. I have to accept that.

(Patricia, counsellor)

Through working with clients over time, the counsellor took opportunities to influence change in perspectives and enable them to make peace with their circumstances. This gave opportunities for clients to live in the here and now and take greater enjoyment from everyday experiences. The counsellor mentioned some situations where she had explored profound and meaningful aspects of a client's sense of self and identity, which seemed to have a lasting impact on her sense of competence:

you can't make it right but you can listen to them. You can be empathic with them. You can be... on side with them whatever- whatever they want you to be.

(Patricia, counsellor)

In such situations, the counsellor seemed to struggle with the realisation that former clients could no longer remember her, despite the significance of their earlier therapeutic relationship. Practitioners may similarly struggle with progressions in a client's condition with dementia, especially when evaluating the impact they have made. This is important to consider in terms of assessing therapeutic benefit for a person living with dementia, emphasising the need for ongoing assessment of impact. Additionally, Patricia suggested the value she placed on feedback from her clients in evaluating her skill as a practitioner, and this may have implications for her confidence and sense of competency.

3.3 | Fostering a therapeutic service

Interviews highlighted factors that appeared to strengthen the therapeutic potential of the service environment, through enhanced support and comfort for people living with dementia.

3.3.1 | Establishing contact

The service co-ordinator highlighted the importance of meeting potential clients and ensuring they understood the reason they had been referred for counselling. Clients were expected to comprehend the need for open exploration of their issues, but a thorough understanding of counselling was not essential to the therapeutic relationship:

I went out and met with them and their support worker, to discuss it between all of us, to get to know

them, the main thing is just for me is make sure ... three basic things to start with really, do they understand what the counselling is and what it's for, that they've been referred, and they're happy to be referred as well.

(Megan, service co-ordinator)

The counsellor highlighted that it was important those referred were 'suitable' for counselling and were able to establish a therapeutic relationship.

So that was at the beginning, we had to talk about, look how and who are we letting into the service, just because they get referred doesn't mean to say that they're okay for counselling and suitable for counselling. So that was a really hard learning curve, about who I can work with, to make it therapeutic.

(Patricia, counsellor)

If the counselling intervention was deemed unsuitable for an individual, Megan and Patricia explored alternative support collaboratively. Judgements of this kind were not based on prearranged criteria for establishing suitability; both parties developed understanding of counselling feasibility over time:

I guess more intuitively as I learnt and as I grew, the judgements became better- well we were all better at it. And now I would say that, very rarely, do I get referred anyone that can't communicate... maybe I've grown as well, so I can work better with them. But there's very rarely now, anyone comes through that I think, oh no I can't work with them.

(Patricia, counsellor)

The service co-ordinator discussed alternative forms of support for individuals when a counselling intervention may not be appropriate. She highlighted that this was an opportunity to develop and integrate other appropriate services into their organisation, to ensure they could offer suitable assistance and support where possible within the centre, as well as signposting clients to other connecting services in the community.

so it's not just about us working with the person it's what, you know what may be missing from ourselves and realising that and kind of signposting elsewhere as well.

(Megan, service co-ordinator)

3.3.2 | Creating a supportive environment

Creating a supportive environment was considered an important factor for fostering a therapeutic service. Whilst this would be seen

as crucial for any individual, for those with dementia and for whom new environments can be difficult, this may be particularly important. In planning the provision of services, the organisation explored ideas with both people with dementia and their relatives. For example, provisions were co-ordinated such as parallel activity groups for people with dementia, enabling dyads to attend the centre together and access counselling.

In addition to offering a diverse range of activities suitable for people living with dementia, the service co-ordinator discussed how they had improved the design of the building to foster a supportive environment.

[People giving feedback] said they've all been very welcomed and are made to feel at home really. [One] lady ... said it felt like a family when she came in, she said I didn't realise we could access it because we weren't [part of the faith], but everybody was really welcoming. So, that's nice feedback to have.

(Megan, service co-ordinator)

The service co-ordinator underlined the importance of the initial personal contact with the client, to ensure the process is clearly explained prior to attendance. She noted that it was beneficial to become acquainted with the organisation and the space in which the counselling was provided. This preliminary contact would also allow for the service co-ordinator and other staff members to address any initial concerns from the clients. Staff were given information about dementia awareness, mindful of the group of individuals accessing the service:

you got to know everybody do you know what I mean? And people are naming you. Even the security man going out the door. "See you after [name]. See you next week". Which is good do you know what- I'm not used to that sort of thing. But er, it's good it's a right family here. And er, I think that's good. It's good. And I think that's what I miss too personally in myself do you know what I mean.

(Shane, person with dementia)

Once sessions ended, the service provided an environment for clients to continue to access informal support. They harnessed positive changes to their confidence and well-being to engage in new experiences, and build their social networks.

Yeah, yeah. I enjoyed it yeah. And er... yeah. I made good friends too. Which- and at the end of the day, I will. I probably still will, come do you know what I- even if it's only just to get a cup of tea, you know what I mean sit and- cos I've got used to- a couple of the lads out there too which... I think it's, it's a good thing to talk too. Cos I used to keep a lot of things locked up inside my head because... you had to, to survive really.

(Shane, person with dementia)

4 | DISCUSSION

This study aimed to explore the factors necessary to forming a therapeutic relationship to support the delivery of counselling to people living with dementia. Themes developed from discussion with the service counsellor and co-ordinator emphasised the importance of therapist attributes in nurturing such a relationship, with importance placed on practice philosophy and capacity to appreciate the lived experience of their clients. This was also highlighted by clients who expressed their comfort in disclosing information, and viewed the therapist as an impartial listener (Griffiths et al., 2020). Based on this philosophy, a reciprocal therapeutic connection, one that involves open communication from the client and understanding from the counsellor, is central to the effectiveness of the intervention.

Interventions that exclude clients with communicative difficulties caused by dementia are common within existing literature (Paukert et al., 2010). An understanding of the potential impact of counselling for people with dementia helped to form a basis for the practitioner to work flexibly to the needs and abilities of people affected by dementia, and the unique challenges associated with the condition. This is supported by Van Werde (2015), who stressed the importance of professionals being open to working with clients with different levels of cognitive functioning. It is furthermore important that practitioners appreciate the potential impact of counselling for people living with dementia. Whilst depression and anxiety are commonly associated with dementia, the symptoms of depression are often masked, suggesting that prevalence may be even higher than estimates suggest (Winter et al., 2011). Therefore, targeting these symptoms through counselling interventions could help to reduce distress for both individuals living with the condition and those supporting them. This intervention overcame some common challenges involving access and comfort, as a result of being embedded within a dementia-friendly service providing allied support to people affected by dementia. This not only meant that avoidable barriers to engagement could be identified and overcome, but also an integrated service meant that individuals could receive appropriate follow-on support or alternatives to counselling if deemed necessary.

Practitioners should also be mindful of practical and psychological barriers for family carers to engage in a therapeutic relationship. Individuals may feel cautious about disclosing unwanted feelings associated with the caregiver role such as resentment or guilt, for fear that this may reflect negatively on their relationship with their relative (Griffiths et al., 2020). Such feelings may affect a person's commitment to counselling and should be addressed, not only by counsellors at the start of the intervention, but also by referring services. This may encourage potential clients to have an open mind towards the impact that counselling may have on their capacity to care for their relative.

Working with people with dementia is not an area focused upon within the standard counselling and psychotherapy curriculum (BACP, 2020), although dementia brings specific health and social

care difficulties for those living with the condition and their families. Those affected can experience turbulent emotional reactions linked to anticipatory grief, namely a sense of loss that is not exclusively linked to bereavement (Chan et al., 2013; Doka, 2010). These aspects may require unconventional approaches to counselling, in addition to specific therapist skills including in-depth knowledge about the condition, and the extent to which dementia may pose emerging difficulties for relatives (i.e. personality fluctuations or loss of inhibitions). Therefore, practitioners should seek specific professional development in order to provide appropriate intervention. Learning may draw from areas of counselling with similar dynamic needs such as trauma, where therapists are expected to work within and tolerate ambiguity that arises from working in an emotionally intense area (Brown & Courtois, 2019). As the prevalence of dementia increases, it is important that the unique skills and understanding required to work with those with the condition are incorporated into counselling curricula.

5 | IMPLICATIONS

Based on the findings from this exploratory study, a number of recommendations can be made for future counselling endeavours for people affected by dementia. Interventions must be oriented towards person-centred practice and tailored approaches to build relationships and support remaining abilities of clients with dementia. Therapists may help to guide clients affected by dementia to cope with an expected sense of loss, drawing from long-term illness approaches and perspectives acknowledging a cumulative loss of identity (Clare, 2003), loss of cognitive awareness and unpredictable changes (Brown, 2009; McCormack et al., 2017).

The present article provides a basis for considering the wider context for counselling; interventions embedded in a wider dementia-friendly environment for people with dementia may ensure continuation of support beyond counselling, and accommodate additional barriers associated with living with dementia or providing full-time care for a relative.

As symptoms of dementia vary widely between individuals, each person with dementia may require customisations based on their cognitive abilities and needs (Tay et al., 2019). Retention of information is a common issue for people with dementia, and therapists should work to ensure that content is as simple as possible, for example focusing on fewer skills and increased repetition of learning strategies (Stanley et al., 2013). Other effective components to help people with dementia engage with counselling include developing coping skills and using cognitive exercises (Tay et al., 2019).

Recent exploratory work with people with dementia has highlighted three important areas to target within counselling: loss of abilities and sense of self, developing coping mechanisms, and reducing loneliness and promoting inclusion (Birtwell & Dubrow-Marshall, 2018). Supporting individuals to restructure their cognitions to incorporate their condition may help them to adjust to a new sense of self (Lee et al., 2014). Stigma pervades around

dementia, impacting how others react and behave towards those affected (Herrmann et al., 2018).

Finally, innovative and creative techniques may be adopted in order to effectively work with people with dementia, and counsellors may borrow from other areas where standard practice may not be well received or easy to deliver, for example using puppets, drawing and games with children with anxiety (Quakley et al., 2004) or somatosensory psychotherapy for people who have experienced trauma (Fisher, 2019).

6 | LIMITATIONS

The study findings are limited due to the involvement of a single therapist in the intervention delivery. However, the exploratory nature of this work triangulates evidence of the acceptability of counselling for people with dementia from the perspectives of the therapist, service co-ordinator and clients (see also Griffiths et al., 2020). Additionally, the therapist's transparency in their epistemological approach and experiential influences promotes the applicability of this approach in other settings.

A second limitation related to participants in the current study having mild-to-moderate dementia, limiting the extent to which conclusions can be drawn for those with more severe cognitive impairment. Most existing studies do not provide clear information about severity of dementia, making it difficult to draw comparisons between studies. A recent systematic review of studies where information about dementia was provided found that all participants had either mild or moderate dementia, with generally small samples, that is fewer than 10 participants (Tay et al., 2019). Therefore, we do not yet know whether counselling interventions are appropriate for people with advanced dementia, acknowledging that each individual faces unpredictable trajectories of symptom onset and development (Shoemith et al., 2020). Future research should ensure that detailed information is collected about participant diagnoses, symptoms and experiences.

7 | FUTURE STEPS

Future research should identify a core set of strategies and modifications required to effectively deliver counselling interventions for people with dementia. This should specifically consider how well individuals are able to adapt, apply and implement strategies in their lives (Losada et al., 2015), as well as considering the optimal ways to develop and maintain a therapeutic relationship. Additionally, there are no recommendations for the duration of sessions, number of sessions required or optimal length between sessions. Exploration of these issues, as well as developing a standardised set of outcome measures with people with dementia and their families, will help develop the evidence base. This study has presented rich qualitative data, which has demonstrated the acceptability of counselling for people

affected by dementia. We hope that this will inform the design of future mixed-methods research to understand wider determinants of counselling outcomes for people with dementia and their relatives.

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REFERENCES

- Arvanitakis, Z., & Bennett, D. A. J. J. (2019). What is dementia? *The Journal of the American Medical Association* 322(17), 1728–1728.
- BACP (2020). Counselling skills competence framework [online]. Retrieved from <https://www.bacp.co.uk/media/8890/bacp-counselling-skills-competence-framework-may20.pdf>
- Birtwell, K., & Dubrow-Marshall, L. (2018). Psychological support for people with dementia: A preliminary study. *Journal of Counselling and Psychotherapy Research*, 18(1), 79–88.
- Brown, K. (2009). Making sense of dementia. *Therapy Today*, 20(4), 34–37.
- Brown, L. S., & Courtois, C. A. (2019). Trauma treatment: The need for ongoing innovation. *Practice Innovations*, 4(3), 133.
- Burns, A., Guthrie, E., Marino-Francis, F., Busby, C., Morris, J., Russell, E., Margison, F., Lennon, S., & Byrne, J. (2005). Brief psychotherapy in Alzheimer's disease: Randomised controlled trial. *The British Journal of Psychiatry*, 187(2), 143–147.
- Carey, T. A., Mansell, W., & Tai, S. (2015). *Principles-based counselling and psychotherapy: A method of levels approach*. Routledge.
- Carpenter, B., Ruckdeschel, K., Ruckdeschel, H., & Haitsma, K. V. (2003). REM psychotherapy: A manualized approach for long-term care residents with depression and dementia. *Clinical Gerontologist*, 25(1–2), 25–49.
- Chan, D., Livingston, G., Jones, L., & Sampson, E. L. (2013). Grief reactions in dementia carers: A systematic review. *International Journal of Geriatric Psychiatry*, 28(1), 1–17.
- Clare, L. (2003). Managing threats to self: Awareness in early stage Alzheimer's disease. *Social Science and Medicine*, 57(6), 1017–1029.
- Cohen-Mansfield, J., Dakheel-Ali, M., Marx, M. S., Thein, K., & Regier, N. G. (2015). Which unmet needs contribute to behavior problems in persons with advanced dementia? *Psychiatry Research*, 228(1), 59–64.
- Cooper, M. (2008). *Essential research findings in counselling and psychotherapy: The facts are friendly*. Sage.
- Doka, K. J. (2010). Grief, multiple loss and dementia. *Bereavement Care*, 29(3), 15–20.
- Fauth, E. B., Jackson, M. A., Walberg, D. K., Lee, N. E., Easom, L. R., Alston, G., Ramos, A., Felten, K., Larue, A., & Mittelman, M. (2019). External validity of the New York University Caregiver Intervention: Key caregiver outcomes across multiple demonstration projects. *Journal of Applied Gerontology*, 38(9), 1253–1281.
- Finlay, L. (2016). *Relational integrative psychotherapy*. Wiley Online Library.
- Fisher, J. (2019). Sensorimotor psychotherapy in the treatment of trauma. *Practice Innovations*, 4(3), 156.
- Goodkind, M. S., Gyurak, A., McCarthy, M., Miller, B. L., & Levenson, R. W. (2010). Emotion regulation deficits in frontotemporal lobar degeneration and Alzheimer's disease. *Psychology and Aging*, 25(1), 30.
- Griffiths, A. W., Shoemith, E., Sass, C., Nicholson, P., & Charura, D. (2020). Relational counselling as a psychosocial intervention for dementia: Qualitative evidence from people living with dementia and family members. *Dementia*, 1–8.

- Herrmann, L. K., Welter, E., Leverenz, J., Lerner, A. J., Udelson, N., Kanetsky, C., & Sajatovic, M. (2018). A systematic review of dementia-related stigma research: Can we move the stigma dial? *The American Journal of Geriatric Psychiatry*, 26(3), 316–331. <https://doi.org/10.1016/j.jagp.2017.09.006>
- Kiosses, D. N., Gross, J. J., Banerjee, S., Duberstein, P. R., Putrino, D., & Alexopoulos, G. S. (2017). Negative emotions and suicidal ideation during psychosocial treatments in older adults with major depression and cognitive impairment. *The American Journal of Geriatric Psychiatry*, 25(6), 620–629.
- Lambert, M. J., Garfield, S. L., & Bergin, A. E. (2004). *Handbook of psychotherapy and behavior change*. John Wiley & Sons New York.
- Lee, S. M., Roen, K., & Thornton, A. (2014). The psychological impact of a diagnosis of Alzheimer's disease. *Dementia*, 13(3), 289–305.
- Lopez, O. L., Becker, J. T., Sweet, R. A., Klunk, W., Kaufer, D. I., Saxton, J., Habeych, M., & Dekosky, S. T. (2003). Psychiatric symptoms vary with the severity of dementia in probable Alzheimer's disease. *The Journal of Neuropsychiatry Clinical Neurosciences*, 15(3), 346–353.
- Losada, A., Márquez-González, M., Romero-Moreno, R., Mausbach, B. T., López, J., Fernández-Fernández, V., & Nogales-González, C. (2015). Cognitive-behavioral therapy (CBT) versus acceptance and commitment therapy (ACT) for dementia family caregivers with significant depressive symptoms: Results of a randomized clinical trial. *Journal of Consulting Clinical Psychology*, 83(4), 760.
- McCormack, L., Tillock, K., & Walmsley, B. (2017). Holding on while letting go: Trauma and growth on the pathway of dementia care in families. *Journal of Aging and Mental Health*, 21(6), 658–667.
- Moss, D. (2001). The roots and genealogy of humanistic psychology. In K.J. Schneider, J.F.T. Bugental, & J. Fraser Pierson (Eds.), *The handbook of humanistic psychology: Leading edges in theory, research, and practice* (pp. 5–20). SAGE Publications.
- Nolan, M., Brown, J., Davies, S., Nolan, J., & Keady, J. (2006). The Senses Framework: improving care for older people through a relationship-centred approach. Getting Research into Practice (GRiP) Report No 2.
- Nolan, M. R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond 'person-centred' care: A new vision for gerontological nursing. *Journal of Clinical Nursing*, 13, 45–53.
- Olazarán, J., Reisberg, B., Clare, L., Cruz, I., Peña-Casanova, J., Del Ser, T., Woods, B., Beck, C., Auer, S., & Lai, C. (2010). Nonpharmacological therapies in Alzheimer's disease: A systematic review of efficacy. *Dementia and Geriatric Cognitive Disorders*, 30(2), 161–178.
- Orgeta, V., Qazi, A., Spector, A. E., & Orrell, M. (2014). Psychological treatments for depression and anxiety in dementia and mild cognitive impairment. *Cochrane Database of Systematic Reviews*, (1), CD009125.
- Orlinsky, D. E., Grawe, K., & Parks, B. K. (1994). Process and outcome in psychotherapy: Noch einmal. In A. E. Bergin, & S. L. Garfield (Eds.), *Bergin & Garfield's handbook of psychotherapy and behavior change* (4th ed., pp. 270–376). Wiley.
- Orlinsky, D., Ronnestad, M., & Willutzki, U. (2004). Fifty years of psychotherapy process-outcome research: Continuity and change. In M. Lambert (Ed.), *Bergin and Garfield's handbook of psychotherapy and behavior change* (5th ed., pp. 307–390). Wiley.
- Paukert, A. L., Calleo, J., Kraus-Schuman, C., Snow, L., Wilson, N., Petersen, N. J., Kunik, M. E., & Stanley, M. A. (2010). Peaceful mind: An open trial of cognitive-behavioral therapy for anxiety in persons with dementia. *International Psychogeriatrics*, 22(6), 1012–1021.
- Paul, S., & Charura, D. (2015). An Introduction to the Therapeutic Relationship in Counselling and Psychotherapy. Sage.
- Paul, S., & Haugh, S. (2008). The relationship not the therapy? What the research tells us. In S. Paul, & S. Haugh (Eds.), *The therapeutic relationship: Perspectives and themes* (pp. 9–22). PCCS Books.
- Prince, M., Ali, G. C., Guerchet, M., Prina, A. M., Albanese, E., & Wu, Y. T. (2016). Recent global trends in the prevalence and incidence of dementia, and survival with dementia. *Alzheimer's research & therapy*, 8(1), 1–13.
- Prochaska, J. O., & Norcross, J. C. (2018). *Systems of psychotherapy: A transtheoretical analysis*. Oxford University Press.
- Quakley, S., Reynolds, S., & Coker, S. (2004). The effect of cues on young children's abilities to discriminate among thoughts, feelings and behaviours. *Behaviour Research and Therapy*, 42(3), 343–356.
- Rogers, C. R. (1959). A theory of therapy, personality, and interpersonal relationships: As developed in the client-centered framework. In S. Koch (Ed.), *Psychology: A study of a science, Vol. 3: Formulations of the person and the social context* (pp. 184–256). McGraw-Hill New York.
- Salzman, C., Jeste, D., Meyer, R. E., Cohen-Mansfield, J., Cummings, J., Grossberg, G., Jarvik, L., Kraemer, H., Lebowitz, B., & Maslow, K. (2008). Elderly patients with dementia-related symptoms of severe agitation and aggression: Consensus statement on treatment options, clinical trials methodology, and policy. *The Journal of Clinical Psychiatry*, 69(6), 889.
- Scholey, K. A., & Woods, B. T. (2003). A series of brief cognitive therapy interventions with people experiencing both dementia and depression: A description of techniques and common themes. *Clinical Psychology and Psychotherapy*, 10(3), 175–185.
- Shoosmith, E., Griffiths, A. W., Sass, C., & Charura, D. (2020). Effectiveness of counselling and psychotherapeutic interventions for people with dementia and their families: A systematic review. *Ageing & Society*, 1–28. <https://doi.org/10.1017/S0144686X2000135X>
- Smith, J., & Firth, J. (2011). Qualitative data analysis: The framework approach. *Nurse Researcher*, 18(2), 52–62.
- Spector, A., Charlesworth, G., King, M., Lattimer, M., Sadek, S., Marston, L., Rehill, A., Hoe, J., Qazi, A., & Knapp, M. (2015). Cognitive-behavioural therapy for anxiety in dementia: Pilot randomised controlled trial. *The British Journal of Psychiatry*, 206(6), 509–516.
- Stanley, M. A., Calleo, J., Bush, A. L., Wilson, N., Snow, A. L., Kraus-Schuman, C., Paukert, A. L., Petersen, N. J., Brenes, G. A., & Schulz, P. E. (2013). The Peaceful Mind program: A pilot test of a cognitive-behavioral therapy-based intervention for anxious patients with dementia. *The American Journal of Geriatric Psychiatry*, 21(7), 696–708.
- Tay, K.-W., Subramaniam, P., & Oei, T. P. (2019). Cognitive behavioural therapy can be effective in treating anxiety and depression in persons with dementia: A systematic review. *Psychogeriatrics*, 19(3), 264–275. <https://doi.org/10.1111/psyg.12391>
- Van Werde, D. (2015). Pre-therapy and working on contact. In: C. Lago, & D. Charura (Ed.). *person centred counselling and psychotherapy origins, developments and contemporary applications*. (2016). Open University Press, McGraw-Hill Education.
- Waldorff, F. B., Buss, D. V., Eckermann, A., Rasmussen, M. L. H., Keiding, N., Rishoj, S., Siersma, V., Sorensen, J., Sorensen, L. V., Vogel, A., & Waldemar, G. (2012). Efficacy of psychosocial intervention in patients with mild Alzheimer's disease: The multicentre, rater blinded, randomised Danish Alzheimer Intervention Study (DAISY). *British Medical Journal*, 345, e4693. <https://doi.org/10.1136/bmj.e4693>
- Winter, Y., Korchounov, A., Zhukova, T., & Bertschi, N. (2011). Depression in elderly patients with Alzheimer dementia or vascular dementia and its influence on their quality of life. *Journal of Neurosciences in Rural Practice*, 2(1), 27.
- Young, R., & Valach, L. (2016). Action and language: Contextual action theory in counselling. *Psychologie Française*, 61(1), 31–42.

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