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**Adapting and optimizing Problem Adaptation Therapy (PATH) for people with mild-moderate dementia and depression**

Catherine McCombie<sup>1</sup> MSc; Elizabeth Cort<sup>2</sup> MSc, Rebecca L. Gould<sup>2</sup> PhD DClinPsy; Dimitris N. Kiosses<sup>3</sup> PhD; George S. Alexopoulos<sup>3</sup> PhD; Robert Howard<sup>2</sup> PhD; Vanessa C. Lawrence<sup>1</sup> PhD

1 = Department of Health Services and Population Research, Institute of Psychiatry, Psychology, and Neuroscience, King's College London

2 = Division of Psychiatry, University College London

3 = Weill-Cornell Institute of Geriatric Psychiatry

Corresponding Author: Dr Vanessa Lawrence, Social Epidemiology Research Group, Health Services and Population Research Department, Institute of Psychiatry, Psychology, and Neuroscience, King's College London, PO26, The David Goldberg Centre, De Crespigny Park, London, SE5 8AF. Tel: +44 (0)20 7848 5071. Email: [Vanessa.c.lawrence@kcl.ac.uk](mailto:Vanessa.c.lawrence@kcl.ac.uk)

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**Key words:** Dementia, Alzheimer's, depression, qualitative, experiences, perspectives, intervention

**Abstract**

*Objectives:* To adapt and optimize problem adaptation therapy for depression in dementia by grounding it in the lives of people with dementia, caregivers and clinicians. *Methods:* A person-centred qualitative approach was taken to elicit the unique cognitive, psychological and social needs of people with dementia relevant to the adaptation of the intervention. A two-stage design was used: the first involved interviews and focus groups to identify priorities and

concerns surrounding depression in dementia, the second trialling of the adapted intervention. *Participants:* Ten people with dementia and nine caregivers participated in individual interviews, 35 healthcare practitioners and clinical academics with experience of working with dementia participated in focus groups. *Results:* The findings highlight the importance of addressing key themes that typified the experience of depression among people with dementia including: a profound sense of isolation and role loss, the feeling of being both a burden and poorly understood, polarised thinking, interpersonal tensions, diverging views among carers and people with dementia about their capabilities, and changeability in cognitive ability and mood. These themes were used to inform adaptation of the intervention manual, ensuring that its content and delivery addressed the concerns of both people with depression and dementia and those who support them. *Conclusions:* Implications for PATH included a focus on facilitating open communication, supporting the continuation of valued roles, and improving confidence.

## **Objective**

Depression in dementia is common, with around half of people with Alzheimer's disease experiencing depression<sup>1,2</sup>, compared to prevalence rates of around a third in older adults without dementia<sup>3</sup>. The combined effect of depression with a disabling condition is profound, leading to reduced quality of life for people with dementia and their caregivers<sup>1</sup>, exacerbating cognitive and functional impairments<sup>4</sup>, increasing mortality<sup>5</sup>, and worsening care outcomes by increasing caregiver burden and risk of transition to residential care<sup>6,7</sup>. Antidepressant drugs are often prescribed to people with dementia<sup>8</sup>, yet clinical trials and meta-analyses have found no superiority of antidepressants over placebo<sup>9</sup>. A recent Cochrane review of conventional psychological therapies for depression in dementia found only modest benefits<sup>10</sup>. Effective support to help people with dementia manage and improve depression is therefore urgently needed.

Problem-solving therapy has been used to treat depression in older adults without dementia<sup>11</sup>. Kiosses et al.<sup>12-17</sup> built on problem-solving therapy principles and incorporated

emotion regulation models to develop Problem Adaptation Therapy (PATH), a psychological therapy for depression in older adults with pronounced cognitive impairment. PATH is conducted with the person and their caregiver, taking into account the impact of cognitive impairment on functioning and engagement with therapy, and allowing caregivers to support implementation of therapeutic techniques. Kiosses et al.<sup>12,13</sup> found that PATH was effective at treating depression and disability in people with depression and significant cognitive impairment, a promising result that suggests offering this novel therapy to people with diagnosed dementia and depression may also be effective.

The progressive nature of dementia, with worsening cognitive and functional impairments, means that people with more advanced impairments may struggle with the structure, pace, and content of traditional PATH sessions. This necessitates further adaptation and elaboration of PATH to ensure people with a clinical diagnosis of dementia, including those in the moderate stages, and experiencing worsening impairments are able to fully engage with, and benefit from, this intervention. Secondly, further research is needed to adapt PATH to be delivered by clinicians with varying professional backgrounds, and within different healthcare settings. Therefore, the aim of this study is to adapt and optimize PATH to be delivered to people with depression and dementia by staff with a range of professional backgrounds as part of routine healthcare. Qualitative, iterative methods will be used to help ensure that the intervention is grounded in the lives and perspectives of those who will use it and thereby reflect the unique cognitive, psychological and social circumstances associated with dementia. Following this adaptation phase, the adapted intervention will be tested in a full randomised controlled trial as part of the PATHFINDER trial.

## **Methods**

### *Study design*

We used a two-stage design to elicit feedback on PATH, using rigorous qualitative research techniques and adapting the intervention in an iterative way. The study was approved by Wales Research Ethics Committee 4, REC Reference 18/WA/0209.

### *Participants*

In Stage 1, fifteen potential participants were identified by clinicians in Memory Clinics and Community Mental Health Teams (CMHTs), and consent obtained to pass their details to the research team. Following screening, ten people with dementia were recruited, along with

nine of their caregivers. Participants passed screening if they were diagnosed with Alzheimer's disease or mixed dementia, had a caregiver who spent at least three hours a week with them over different visits, and scored above ten on the Standardised Mini Mental State Examination<sup>18</sup>, and above seven on the Cornell Scale for Depression in Dementia<sup>19</sup>. All participants were assessed at both study stages to have capacity to consent by a research nurse with extensive experience of working with people with dementia, and written informed consent was obtained from all participants. We selected participants to give a range of perspectives, according to depression and dementia severity, ethnicity, age, gender, and caregiver relationship. Half of the participants were recently diagnosed with Alzheimer's disease (in the past six months), but reported awareness of memory problems for some time before diagnosis.

Participants for four focus groups were clinicians who responded to an invitation to participate sent to Memory Clinics and CMHTs in north London. The fifth focus group involved PATHFINDER study research collaborators, experts in the field of dementia and mental health. A Patient and Public Interest (PPI) meeting involving six people with dementia, recruited from an Age UK dementia support group, was conducted to help interpret emerging themes. Participant characteristics are reported in Table 1. Participants provided informed consent and agreed to confidentiality in each group.

All stage one interview participants agreed to take part in stage two, but only five dyads were able to participate: two declined as caregivers were too busy, one person with dementia was experiencing serious health problems, and two dyads were uncontactable.

#### *Data collection*

In Stage 1, we interviewed each person with dementia and their caregiver separately. Interviews lasted 20-50 minutes, guided by a flexible topic schedule. This encompassed discussion of situations or problems that trigger negative emotions or inhibit positive emotions, feasibility and acceptability of strategies to reduce the negative impact of behavioural and functional limitations, how best to involve carers in PATH, and how to adapt the intervention to an individual's circumstances and needs. The focus group topic schedule included discussion of perceived priorities and needs of people with dementia and depression and their caregivers, and the challenges and solutions of using PATH approaches with this population. Emerging themes were discussed with participants in the PPI focus group, and feedback on their perspectives was sought and incorporated into the analysis. Two researchers (CM and EC) conducted the interviews and focus groups, which were audio recorded and

transcribed.

In Stage 2, we trialled two sessions of the adapted intervention, focussing on testing the newly adapted manual and worksheets with participants. Sessions took place in participants' homes, a week apart. Informed consent was taken from both parties before session one. We used think-aloud (TA) techniques to guide session plans<sup>20</sup>. TA techniques are based on the idea that people can verbalise their internal processes as they complete a task<sup>21,22</sup>. A TA approach is valuable in evaluating an intervention for people with dementia, as it allows people with dementia to openly talk about how they are experiencing the intervention session as it happens, removing the need to recall session details in a later feedback interview.

Taking into consideration the need for participants to feel comfortable talking openly about their concerns or feedback, instructions given at the beginning of each session explained the value of receiving open and immediate reactions and highlighted that participants could stop to ask questions at any point. One researcher (CM) conducted the sessions, which were audio recorded then transcribed, with research notes taken throughout of body language, expression and tone indicating where confusion or uncertainty was present.

#### *Analysis*

In Stage 1, we analysed transcripts using Braun and Clark's thematic analysis guidelines<sup>23</sup> with an inductive approach, and a practical focus around identifying aspects from participants' experiences that had implications for intervention adaptation. Data from each group was analysed separately to identify issues and perspectives pertinent to each group. Transcripts were analysed by CM with a proportion also analysed by VL and EC.

Key themes and interpretations were discussed with the research team, including PPI representatives. The PATH manual developed by Kiosses et al.<sup>12</sup> was then adapted in collaboration with the original authors to ensure that the intervention manual reflected the priorities and concerns of those with dementia and the caregivers and clinicians who support them. The adaptation maintained the main theory, therapeutic approaches, and techniques of PATH.

In Stage 2, we analysed transcripts and research notes from the think-aloud sessions with the specific focus of gathering feedback on whether the adapted manual required further changes. Descriptions of problems encountered and direct feedback from each participant were written for each session, and then cross referenced with other sessions and participants to see if the issue was repeated. A feedback document was prepared containing recommendations and

suggestions for further changes to the intervention manual, and following further adaptation, the manual was approved by the manual adaptation team.

## **Results**

### **Stage one**

Four main themes arose from analysis, each capturing important elements of the experience of depression in dementia that had implications for the content and delivery of the intervention. Themes are presented here with initial focus on the views of people with dementia, including PPI group participants. The views of caregivers and healthcare professionals are provided where they reveal further nuances or differing perspectives. These findings informed the adapted PATH manual and subsequent training to PATH Therapists (meaning anyone delivering PATH) in the PATHFINDER RCT. Quotes for each theme are presented in Table 2, and implications from each theme that guided the intervention adaptation can be found in Table 3.

#### ***Theme one – Experience of Loss***

##### **Loss of social contact**

This was reported by most as a key factor in depression in dementia. People with dementia reported many ways that dementia affects their social lives, from struggling to talk in public places due to confusion and levels of background noise, embarrassment at forgetfulness during conversations or at having less to talk about due to reduced activity, and through irritability or frustration at not understanding others or being understood themselves. Reduced family contact, with children moving away, combined with reduced mobility and ability to travel themselves, was identified by all participants as a contributor to depression.

##### **Loss of functioning and confidence**

People reported frustration and loss of confidence resulting from being unable to undertake day-to-day activities such as housework, personal care, and visiting friends without support from caregivers. They felt this caused depression directly, and also indirectly by exacerbating fears of being a burden.

This theme captured striking differences in perspectives between people with dementia, caregivers, and clinicians. Caregivers frequently felt their relative could be doing more but chose not to, and clinicians suggested that people with dementia's awareness of a supportive infrastructure could both compensate for and reinforce their reduced independence, thereby

contributing to excess disability. Caregivers reflected that “bad memory days” lead to worsened mood, but neither caregivers nor clinicians acknowledged their potential impact on confidence. In contrast, several people with dementia expressed sadness that others were frustrated with them for doing things too slowly, and said that this made them not want to do things.

#### Loss of role or identity

Most people reported losing important roles in their lives since developing dementia, such as work, community, and spiritual roles, and stated this was a primary factor in depression. Clinicians focused primarily on change in traditional gender roles, but did not discuss other roles and aspects of people with dementia’s identity.

### *Theme two – Pertinent cognitive and emotional aspects of depression in dementia*

#### Self-esteem and internalised stigma

Many people used self-critical or self-stigmatising language that likely reflected how they saw themselves. For example, “useless”, “incapable”, “backwards”, “falling apart”, “a nutter”, “nobody”, “not important”. Carers reported that any existing low self-esteem in their relative was exacerbated by dementia.

#### Polarised thinking

Some people viewed dementia as something they had to adapt life to, but others seemed to feel that dementia meant their lives were over, and were resigned to merely existing while they waited to die.

The latter outlook underpinned several other themes, particularly suicidality, low self-esteem and self-stigma, and relationship tensions. Relationship tensions were evident as people with this attitude appeared less inclined to try to help themselves, generating frustration among caregivers, and irritability on both sides. The perspective of life being over was more prominent in those with more severe depression and low motivation.

#### Anxiety

People frequently reported anxiety, including worrying about forgetting things, making mistakes, the future, and the impact of dementia on their families. Anxiety affected many areas of their lives, with people reporting that anxiety stopped them from doing things just as much as their dementia or depression symptoms. Caregivers felt anxiety lead to irritability, which then lowered mood. Clinicians agreed that anxiety and depression are often intertwined, and hard to treat in isolation.



## Burden

Most people with dementia reported feeling like a burden, with some suggesting that their families would be better off without them. Many felt this was their responsibility to manage, by keeping things to themselves rather than talking to others about how they were feeling, as talking about worries was considered to cause their caregiver to experience more stress and worry. Caregivers also felt that they had to manage their relatives' fears of being burdensome, by not sharing their worries or concerns with them. Clinicians thought that engaging in PATH together might help reduce worries about burden in both, as it would help them talk and develop coping strategies together.

### *Theme three – Caregiver involvement challenges*

All participants thought the involvement of a caregiver in therapy would be beneficial to all involved, with caregivers hopeful that it would help improve their own understanding of how to help manage their relative's mood. However, all groups acknowledged that this would introduce specific challenges.

#### Caregivers' own physical and mental health challenges

People with dementia worried about the additional burden on their caregivers on top of their current demands. Caregivers and clinicians identified issues that may affect caregivers' ability to be involved in PATH, including their own mental and physical health problems, other caring responsibilities, and maintaining paid employment.

#### Differing perspectives

People with dementia reported it is hard to understand what dementia is like unless you have it, and felt that caregivers struggled to understand how it eroded their sense of self and made everyday life difficult. Caregivers reported that they would identify more difficulties than their relative with dementia, stating that their relative often forgets problems or does not see difficulties as being problematic, but worried about causing upset by giving different perspectives. Caregivers reported anxiety about disagreeing with their relative in therapy sessions, as they were concerned about starting arguments.

#### Relationship tensions

People with dementia and their caregivers revealed that the main interpersonal problem they experienced was irritability with each other, which was typically reported as being an effect of dementia and forgetfulness. However, clinicians reported concerns about interpersonal

conflicts and underlying relationship problems, anxiety about managing conflict, and concern that sessions could become more like relationship therapy.

#### ***Theme four – Preferences for therapy delivery***

##### Language and tone

All participant groups mentioned the importance of language and tone when talking to people with dementia, and of making sure that clinicians did not appear patronising. People with dementia typically identified with more general terms such as memory problems, being fed up, and feeling down, rather than dementia and depression, and felt these words might be off-putting, although some did prefer the term depression. Caregivers stressed the need for sensitivity, using relevant examples, and asking questions in small steps to avoid causing confusion. Clinicians highlighted that people with dementia are often very aware of being talked down to.

##### Flexibility

All participants referenced the value of flexibility in sessions. Some people talked about how they can struggle to find words, so flexibility over session length would be helpful as there would be times when they found it harder to talk. Some suggested that suitable length depended on the content of the session, with people disliking numerous questions or feeling like they were being talked at for a long time. People had different preferences over session location, with some preferring to leave the house for appointments to give them something to do, and some preferring a clinician visit them so they need not worry about travel. Clinicians agreed on the importance of flexibility for engagement, but reported concerns over how that would work in a practical sense in the clinical setting.

##### Home Practice

Most people liked the idea of home practice, but said it should be simple to avoid making them feel overwhelmed. Some reported diminishing reading and writing abilities, and worried about completing homework for this reason, but caregivers were keen to provide help and support as they thought it would be useful. Clinicians supported using worksheets, but suggested participants were more likely to engage with homework if it was used according to need rather than prescriptively.

#### **Stage two**

Feedback consisted of specific recommendations for changes to the manualised intervention, based on difficulties encountered and feedback received from participants. Changes included session structure, information and instructions, wording, adjusting information and instructions for people with different levels of dementia severity and functioning, and highlighting where therapists need to be aware of particular issues that might be encountered and how to manage these.

For example, despite describing comprehensive problem lists in session one, several people with dementia said that whether they actually view something as a problem depends on the mood they are already in - if they wake up feeling depressed, they will experience something as much more troublesome than if they had woken up feeling neutral or happy. Many people reported that their mood changes regardless of what is going on around them, leaving them feeling out of control with respect to their moods and emotions. Insights such as this enabled the manualised intervention to be sensitive to individual variation in how people with dementia experience depression, and to guide therapists to be more sensitive and use judgement about how to follow the manual with each person.

Participants reported many positives of the sessions, including having practical suggestions and approaches to problems, a chance to talk through things and make plans, and that it left them with a sense of hope for the future. Some feedback comments are summarised in Table 4.

## **Conclusions**

The findings illustrate the difficulties experienced by people with moderate dementia and depression and their caregivers, and highlight the many opportunities for intervention that a talking therapy focused around problem solving and emotion regulation could address in this population. Adjusting to a new reality of challenges and loss affects emotions, leading to reduced confidence and self-esteem, and anxiety around reduced functioning. Findings are consistent with Kitwood's theory of Personhood<sup>24</sup>, as often a sense of loss and reduced functioning was inadvertently exacerbated by behaviours of caregivers, such as stopping the person with dementia doing things or speaking on their behalf. Key recommendations for intervention adaptation based on the findings of this study include: supporting people with dementia to continue with valued roles but also adjust to changes; supporting open discussion with caregivers around activities and care arrangements to optimize independence and reduce

relationship tensions and fears around burden; and supporting people with dementia to maintain social activities to create a supportive community and increase confidence and self esteem. These key suggestions align with Fazio's recommendations for person-centred care in dementia<sup>25</sup>. Involving caregivers in the intervention adds a valuable dimension to therapy, allowing joint discussion about manageable activities for the person with dementia.

The findings highlight the value of listening to the perspectives of people with dementia themselves, rather than relying on informants, as much research still does<sup>26</sup>. Contrary to Burke et al.<sup>27</sup>, people with dementia mostly gave similar descriptions of their depressive symptoms and behaviours as their relatives, but it was beliefs about why certain symptoms and behaviours were present where perspectives diverged. A key example of this being one person with dementia saying she had stopped doing her favourite hobby because she feared making mistakes, while her caregiver had assumed she had just lost interest due to depression. All participants were able to clearly articulate their thoughts, feelings, and motivations, even those with more moderate dementia. Thus, relying solely on clinicians and caregivers perspectives would lead to missing important thoughts and feelings underlying behaviours, and interventions may be less effective.

This has important implications for future research understanding the thoughts, feelings, and behaviours of people with dementia, reinforces the need for research to include their voices, and highlights the value of involving people with dementia in intervention development. It is clear that using person-centred, qualitative methods can give richer and more meaningful understanding of conditions, and could help explain unexpected findings such as Zhu et al.'s findings of no interaction between depression and apathy in people with dementia<sup>28</sup>.

Participants were from a range of cultural, ethnic, and socio-economic backgrounds, suggesting the findings reflect common difficulties across these demographics. However, this may also be problematic as there are cultural differences in how both depression and dementia are experienced<sup>29,30</sup> and clustering several cultures into one small sample may obscure nuances of how better to support people from different backgrounds. Including people with varying dementia severity and education levels, and clinicians with a range of professional backgrounds, has allowed the manualised intervention to be sensitive to a wide range of participant needs and provide real examples of how different techniques can be used with different people. One particular challenge was carer availability - a further iteration of PATH

may be needed so that people with limited access to carers, who are often most in need of support for depression, can also benefit from the support of PATH interventions.

Obtaining feedback and perspectives from these three key stakeholder groups resulted in a therapy that is readily acceptable to those receiving and delivering it, enabled key problem areas to be addressed, and optimized the intervention in advance of its evaluation in the subsequent RCT.

#### **Disclosures/Conflicts of Interest**

No disclosures to report.

#### **Author Contributions**

CM wrote the manuscript and conducted data collection and analysis. EC contributed to data collection and analysis. RLG and RH contributed to manual development and data analysis. DK and GA provided the intervention and manual for adaptation. VL contributed to data analysis and manuscript preparation. All authors reviewed the final manuscript.

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