Individual and Group Psychotherapy with people affected by dementia:

Review questions
- What is the evidence base for psychotherapeutic interventions have been used for people affected by dementia?
- What good practice principles underpin psychotherapeutic interventions for people affected by dementia?

Search strategy:
We will search electronic databases (Cinahl Plus, the Cochrane Library, Embase, Medline and Psychinfo) were searched using the terms (“Dementia” OR “Vascular Dementia” OR “Dementia with Lewy Bodies” OR “Alzheimer’s Disease” “) AND (“psychotherapy” OR “counselling” OR “cognitive therapy” OR “validation therapy” OR “support groups” OR “peer support”) NOT (“cognitive stimulation” OR “rehabilitation”). In addition, we searched the grey literature (including relevant websites and reference lists in articles). Study selection followed the PRISMA guideline for reporting flow of information in systematic reviews of literature (Moher et al, 2009).

Aim of the review:
- To identify the evidence base for psychotherapeutic interventions for people affected by dementia
- To synthesise the evidence for psychotherapeutic interventions for people with dementia.
- To determine good practice principles for psychotherapeutic interventions for people with dementia.
- To scope the range of outcomes of psychotherapy in dementia and the most common mental health comorbidities (i.e. depression and anxiety).

Types of studies to be included
Studies using any type of design will be included if they provide a description or comparison of psychotherapeutic intervention used specifically for people with dementia: trials with or without control groups, observational reports of interventions and case studies.

Inclusion criteria: The study must contain report of a psychotherapeutic intervention focusing on people with dementia. The interventions will be included in the review if they are derived from established psychotherapeutic principles, such as those defined by the BACP.

Exclusion criteria: Studies will be excluded if they do not report results of a psychotherapeutic intervention aimed for people with dementia.

Condition or domain being studied
The domain being studied includes psychological and/or behavioural change arising as the outcome of a psychotherapeutic intervention used with people affected by dementia.

The term “dementia” refers to a range of conditions, the most common of which is Alzheimer’s Disease. There are estimated to be around 36 million people living with dementia worldwide, with this figure expected to rise to 66 million by 2030 and 115 million by 2050 (Alzheimer's Disease International, 2012). The increasing prevalence of dementia, with its associated costs, means that it has become a clear priority area for policy makers as well as researchers. Thus in the UK, the 2009 policy document “National Dementia Strategy: Living well with Dementia” emphasises the importance of early diagnosis so that people are able to take greater control over their condition, to be involved more actively in planning care and thus to “live well” with dementia.
Protocol: Psychotherapy and people affected by dementia - a literature review

The move towards an early and timely diagnosis of dementia is based, at least in part, on the belief that this will facilitate people who receive a diagnosis being able to plan ahead and to take control over their illness. However, it is likely that the emotional weight of a diagnosis combined with the impact of the neurological impairment and social difficulties in talking about the diagnosis mean that for many people affected by dementia it can be extremely difficult to make this adjustment. This process is likely to be further exacerbated by the lack of specialist support provided to people after they have received a diagnosis (Watts et al, 2014).

Given the combination of powerful emotional responses to dementia (Aminzadeh et al, 2007; Connell et al, 2004) and the desire of most people to know about their illness (Quimet et al, 2004; Elson, 2006; Jha, Tabet and Orrell, 2001), it is perhaps unsurprising that psychotherapeutic approaches with people affected by dementia have been consistently reported over the last twenty years. However, the evidence base for this form of working is not clear.

**Participants/population**

**Inclusion criteria**: people with the following types of dementia - Alzheimer’s Disease, Vascular dementia, Lewy-body dementia or a mixed condition.

**Excluding criteria**: people with frontal-temporal dementia; mild cognitive impairment; and those dementias caused by conditions such as the human immunodeficiency virus (HIV), Creutzfeldt-Jakob Disease (CJD), repeated head traumas (Dementia Pugilistica), Huntington’s Disease, Parkinson’s Disease and Down’s Syndrome.

**Intervention/exposure**

**Inclusion criteria**: Group or individual psychotherapeutic interventions aimed at people with dementia that meet the criteria of a definition provided by the British Association of Counselling and Psychotherapy (BACP). Based on this definition, in order for therapeutic interventions to be included, the intervention must be:

- A talking therapy focusing on “talking about life events, feelings, emotions, relationships, ways of thinking and patterns of behaviour” (BACP).
- Occur regularly at specific times and within a specific context.
- Delivered by trained practitioners who have received training and have regular clinical supervision.
- Aim to help participants find a right solution to their problem, understand themselves and others, promote effective change of thinking or behaviour or enhance participants’ wellbeing.

In addition, therapists must attend to a range of therapeutic issues including the need for confidentiality, adopting a non-judgemental approach to participants and work with clients' emotions without becoming emotionally involved themselves.

Applying the above criteria for a psychotherapeutic intervention, we will include a range of widely recognised therapies and other psychological therapeutic activities that have been used in an individual or group setting. These will include:

- Individual therapy
  - Humanistic and transpersonal
  - Psychodynamic
  - Cognitive Analytic Therapy (CAT)
  - Cognitive Behaviour therapy (CBT)
- Validation Therapy
vi. Other forms of work that are not explicitly identified as involving counselling or psychotherapy, provided that it meets the above mentioned criteria.

b. Group Psychotherapy
   i. exploratory
   ii. directive (including psycho-educational where this is more than just giving out information)
   iii. Validation Therapy

c. General articles on Psychotherapy
   i. Process research

We will also apply a time limit and only include studies that were published from 1st January 1997 onwards. The reason for this criterion is that a review of literature on this topic was published by Cheston (1998), where papers published before 1st January 1997 were reviewed.

**Exclusion criteria:** Other forms of therapeutic work that overlap with psychotherapy but which do not otherwise meet the definitions provided above. These are, specifically, occurring regularly, being delivered by trained therapists who receive supervision, and focussing on talking about feelings, ways of thinking or patterns of behaviour with the objective of resolving difficulties, developing understanding of the self and others or finding new ways to cope or different solutions to problems.

Based on these exclusion criteria, we will **not** include the following therapeutic interventions.

The following is not an exhaustive list:

a. Cognitive Stimulation and Rehabilitation
b. Art and Music therapy
c. Reminiscence
d. Recovery approaches
e. General reviews of non-pharmacological work that do not have a specific focus on psychotherapy
f. Couple and family therapy - where the focus is on a single family unit – This is because family therapy in dementia was recently reviewed Benbow and Sharman (2014).

**Search dates.** Cheston (1998) reviewed this literature before the 1st January 1997, and we will therefore only include papers published between the 1st January 1997 and 2015.

**Comparator/control**

Not specified. Some studies may have control groups, whilst others are likely to be qualitative analyses of interventions or case reports.

**Context.**

No defined setting

**Outcome**

Not specified. One aim of the review will be to scope the range of outcomes of psychotherapy that have been identified.

**Data extraction (selection and coding)**

The articles will be searched for and downloaded by member of the research team (AI and RC). AI will screen the identified articles and apply the inclusion and exclusion criteria to select the relevant research papers.
**Study selection** – will be performed following the PRISMA guideline for reporting flow of information in systematic reviews of literature (Moher et al, 2009). The review will be performed in the following stages: identification, screening, eligibility check and inclusion in the review. The selection of studies will be done by two researchers and discrepancies will be resolved by discussion (n=1,596).

**Identification** – after running the search in the listed databases and searching the grey literature, all identified studies will be exported into a reference manager (e.g. RefWorks).

**Screening** – the first step of screening the studies will be to review the article titles for potential relevance to the review research questions. The abstracts of all potentially relevant studies will be screened to decide their inclusion or exclusion in the review, and full-text articles of these studies will be downloaded. The references of the included articles will be searched for relevant papers.

**Eligibility check** – an eligibility form will be developed specifically for this review in order to support the decision process of including and excluding studies in the review. The eligibility form will contain a checklist of the inclusion and exclusion criteria for the review.

**Inclusion** – The studies that meet all the inclusion criteria will be included in the review.

**Data extraction** – A data collection form will be developed to extract data from the individual studies in the review. The form will be pilot tested on a random selection of studies prior to conducting the full review. Any adjustments and changes made to improve the form will be documented and justified. The data will be recorded electronically and analysed using qualitative data analysis tools or the SPSS for Windows, as appropriate. The data collection form will contain several broad domains, including theoretical underpinning and justification of the methods; theoretical underpinning of the intervention; population and setting; methodology; participants; study aims; intervention and control groups; type and provision of psychotherapeutic intervention; outcomes; other information and applicability.

If and when necessary, we will contact the corresponding authors to provide required information.

**Risk of bias (quality) assessment**

Since studies using a number of different research designs will be included in the review, we will use a specific assessment tool to evaluate the quality and the risk bias of each type of design included in the review.

The risk of bias tool for randomised and non-randomised controlled trials is adapted from the PEDro-P Scale for randomised and non-randomised controlled trials (Murray et al, 2013), with two additional items added: “Was the allocation sequence adequately generated?” is taken from the Cochrane Collaboration’s tool (Higgins et al, 2011); and “The therapy across the intervention was standardised (e.g. through training, supervision and use of manuals)” is specifically added for this review. For Level III studies, we will follow the procedure adopted by Toms et al (2015) and rate studies in terms of those 28 CONSORT items (Moher et al, 2010) that were relevant to repeated measures studies. The risk of bias assessment will be conducted independently by the two authors with disagreements resolved through discussion.

For analysis of Level IV data we will use the following tools:

- **SCED Scale** – for single participant designs
- **COREQ checklist** – for interviews and focus groups
In order to remain inclusive but minimise the risk of bias, we will grade the level of evidence in each of the included studies.

**Strategy for data synthesis**

The review will be performed in two main parts:

1) The aim of the first part will be to identify the evidence base for individual and group psychotherapy used for people with dementia, and to evaluate the methodological quality of these studies. We will address the evidence of the interventions’ outcomes, effectiveness, methods and outcomes of addressing common mental health comorbidities and applicability.

2) The aim of the second part of the review will be to synthesise the principles of good psychotherapeutic practice in therapies for people with dementia as shown within Level IV (qualitative studies).

**Analysis of subgroups or subsets**

None planned.

**Dissemination plans**

We aim to submit two separate articles for publication relating to the two separate areas of the review, in impactful academic journals, for example the *International Journal of Geriatric Psychiatry*. The findings will also be presented in academic conferences and used to inform the development of interventions.

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**Details of any existing review of the same topic by the same reviews**

None

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Other registration details

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Country: Any

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References


Watts S, Cheston R, Moniz-Cook E, Burley C, and Guss R (2014), Post-diagnostic support for people living with dementia, in R Guss et al (on behalf of the Faculty of the Psychology of Older People, and in collaboration of people living with dementia and the Dementia Workstream