

A systematic review of the effectiveness of Acceptance and Commitment Therapy (ACT) compared with other psychological therapies in managing grief experienced by bereaved spouses or partners of adults who had received palliative care worldwide

## Citation

Jitka Vseteckova, Kerry Jones, Geraldine Boyle, Rebecca Garcia, Abigail Methley. A systematic review of the effectiveness of Acceptance and Commitment Therapy (ACT) compared with other psychological therapies in managing grief experienced by bereaved spouses or partners of adults who had received palliative care worldwide. PROSPERO 2020 CRD42020191394 Available from:  
[https://www.crd.york.ac.uk/prospERO/display\\_record.php?ID=CRD42020191394](https://www.crd.york.ac.uk/prospERO/display_record.php?ID=CRD42020191394)

## Review question

How effective is ACT compared with other psychological therapies in managing grief experienced by bereaved spouses/partners of adults who had received palliative care worldwide?

## Searches

The search will include both quantitative and qualitative studies. Search limited to 1980 onwards to fit with timespan ACT has been in use. Language will be limited to English only. The search strategy will be created by an expert in systematic review searching, in collaboration with the authors. A draft MEDLINE search is shown in the table below. Once this strategy is finalised, it will be adapted to the syntax and subject headings of the other databases.

Preliminary databases searched:

PsycINFO, EMBASE, EMCARE, MEDLINE, CINAHL, BNI, AMED

Syntax used for full searches: PsycINFO:

"ACCEPTANCE AND COMMITMENT THERAPY"/

[carer OR carers).ti, ab] [CAREGIVERS/ OR "CAREGIVER BURDEN"/] ("informal care\*").ti, ab

exp SPOUSES/ OR exp COUPLES/ OR exp "FAMILY MEMBERS"/

EMBASE:

exp "ACCEPTANCE AND COMMITMENT THERAPY"/

CAREGIVER/ (carer OR carers).ti, ab ("informal care\*").ti, ab exp FAMILY/

EMCARE:

exp "ACCEPTANCE AND COMMITMENT THERAPY"/

CAREGIVER/ (carer OR carers).ti, ab "informal care\*").ti, ab exp FAMILY/ exp "CAREGIVER BURDEN"/ OR "CAREGIVER BURNOUT"/

MEDLINE:

"ACCEPTANCE AND COMMITMENT THERAPY"/

(carer OR carers).ti, ab ("informal care\*").ti, ab CAREGIVERS/ exp FAMILY/

CINAHL:

"ACCEPTANCE AND COMMITMENT THERAPY"/

(carer OR carers).ti, ab "informal care\*").ti, ab CAREGIVERS/ exp FAMILY/ "CAREGIVER BURDEN"/

### Types of study to be included

We plan to include studies of any design (quantitative, qualitative, mixed-methods or professional practice articles) ACT therapy working with defined sample looking at outcomes under evaluation

### Condition or domain being studied

Anticipatory grief involves grieving for the impending loss of a patient and which has been assumed to improve bereavement outcomes. However, a systematic review by Thomas et al (2014) indicated that low levels of preparedness during caregiving was associated with poor bereavement outcomes, such as prolonged grief disorder. Even if carers, spouses and partners were prepared post death, some individuals still report high levels of mental health problems during bereavement (Thomas et al, 2014). Bonnano et al (2008), report that 10-15% of individuals bereaved following the loss of a patient in receipt of palliative care suffer chronic distress and depression for many years after the loss, while others report acute depression from which they recover in one to two years. Anticipatory grief results from uncertainty as well as trying to cope with what is to come or how a disease will progress.

Acceptance and Commitment Therapy (ACT) is a form of cognitive behavioural therapy (Hayes, Strosahl & Wilson, 2004) which has been growing in popularity since its development in the 1980s. ACT takes a non-pathologising view of mental health, conversely stating that everyone experiences challenges and distress in life.

### Participants/population

Adult (18+) spouses/partners (the latter may be cohabiting or not) of people who had received palliative care. May have a diagnosis of depression/anxiety/grief disorders/adjustment disorder if they have been seen by mental health services, may be subclinical.

### Intervention(s), exposure(s)

Acceptance and Commitment Therapy interventions. Therapist-delivered, self-help and/or online therapies, combination therapies (e.g. aspects of both therapist and self-help or online therapies).

### Comparator(s)/control

Alternative interventions or treatment as usual would be used as comparators.

### Context

A number of strategies and interventions have been discussed but there is a shortage of evidence-based strategies to guide health professionals in providing optimal support while the caregiver is providing care and after the patient's death (Hudson et al, 2012). To exacerbate this further, during the current COVID-19 pandemic access to essential palliative care, including bereavement support, is limited due to high demand. Individuals are unable to be at the bedside of their dying loved ones and to say goodbye or to engage in traditional funeral rituals. Indeed, the most recent guidelines stipulate that support, if any, should be conducted remotely and usually to inform families of the death. What guidance is available pertaining to bereavement support is confined to a series of guidelines on social distancing when planning and

attending (or not) funerals (NHS England, 2020). As a consequence carers, spouses and partners are experiencing increased isolation and suffering (Radbruch et al, 2020).

### Main outcome(s) [1 change]

- Is ACT more effective than standard card in enabling the management of grief in spouses/partners of people who had received palliative care?
- Is ACT also more effective than other types of therapy (such as CBT) in enabling the management of their grief?
- Does ACT improve outcomes such as depression, anxiety, grief disorder and overall quality of life?

Mental health disorders such as anxiety and depression are the largest cause of disability, with 1 in 4 adults diagnosed with a mental health condition in the UK in any given year (NICE, 2019). McLachlan and Gale (2018) found that poor mental health impacts an individual's physical health significantly and can lead to a number of co-morbidities including diabetes, arthritis, cardiovascular disease and chronic obstructive pulmonary disease.

Physical activity has been shown to provide clear health benefits including reduced risk of cardiovascular disease, certain cancers, stress and depression, and improved mental / cognitive health, wellbeing and sleep (Reiner et al., 2013; Warburton et al., 2006) and vice versa, improving mental health has also beneficial impact on physical health. Furthermore, physical activity per se is now recognised as a health outcome by major funding councils and government organisations.

### Measures of effect

Not applicable

### Additional outcome(s) [1 change]

- Is ACT more effective when delivered by a therapist or alternatively through online or self-help modes (or perhaps via combination therapies)?
- Are there any socio-demographic differences (e.g. age, gender) in those who are offered ACT, or in its effectiveness, when compared with other therapies ?

In addition we would be looking at response and attrition rates; acceptability; experiential avoidance and psychological inflexibility (commonly measured by the Acceptance and Action Questionnaire); ACT process (commonly measured by Comprehensive Assessment of Acceptance and Commitment Therapy); valued living (commonly measured by the Valued Living Questionnaire); post-loss grief (commonly measured by the PG-13); perceived ability to control distressing thoughts; psychological distress (can include symptoms of depression and anxiety; commonly measured by HADS, PHQ-9 etc); carer quality of life; service use and utilisation.

Mental health disorders such as anxiety and depression are the largest cause of disability, with 1 in 4 adults diagnosed with a mental health condition in the UK in any given year (NICE, 2019). Symptoms of depression and anxiety are collectively referred to as psychological distress which encompasses a range of mental health experiences which range from mild symptoms to severe psychiatric disease. Utilising population data from the UK Longitudinal Survey, McLachlan and Gale (2018) found that poor mental health impacts an individual's physical health significantly and can lead to a number of co-morbidities including diabetes, arthritis, cardiovascular disease and chronic obstructive pulmonary disease.

### Measures of effect

Not applicable

### Data extraction (selection and coding)

Data for analysis will be extracted from the included studies and managed in an Excel spreadsheet. A data extraction sheet will be developed which will be tailored to the requirements of the review. The data extraction sheet will be tested on three included papers and, where necessary, it will be revised to ensure it can be reliably interpreted and can capture all relevant data from different study designs.

Study selection (both at title/abstract screening and full text screening) will be performed by reviewers, independently. Any disagreements will be solved by consensus or by the decision of a reviewer where necessary. After eliminating the duplicates (studies that are identified more than once by the search engines), an initial screening of titles, abstracts, and summaries (if applicable) will be undertaken to exclude records that clearly do not meet the inclusion criteria. Each record will be classified as 'include' or 'exclude' or 'maybe' with comments to identify relevant and exclude irrelevant literature. The researchers will be inclusive at this stage and, if uncertain about the relevance of a publication or report, it will be left in. The full text will be obtained for all the records that potentially meet the inclusion criteria (based on the title and abstract/summary only). In a second step, all the full text papers will be screened against the inclusion criteria, using a standardized tool. Studies that do not meet the inclusion criteria will be listed with the reasons for exclusion. An adapted PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) flow-chart of study selection will be included in the review [12].

### Risk of bias (quality) assessment

Two reviewers will independently assess the risk of bias for randomized controlled trials using the Cochrane risk of bias tool [15, 16], which includes the following domains: random sequence generation, allocation concealment, blinding of outcome assessors, completeness of outcome data, and selective outcome reporting. We also plan to assess the following additional sources of bias: baseline imbalance and inappropriate administration of an intervention as recommended by the Cochrane Handbook for Systematic Reviews of Interventions [16]. Studies will be judged at high risk of bias if there was a high risk of bias for 1 or more key domains and at unclear risk of bias if they had an unclear risk of bias for at least 2 domains. Authors of papers will be contacted if information is missing.

### Strategy for data synthesis

Each of the included studies will be appraised using a standardised critical appraisal tool. Critical appraisal forms for mixed methods will be tested, such as the Mixed Methods Appraisal Tool (MMAT) Version 2018 [13] and Critical Appraisal Skills Programme (CASP) tool [14]. Both suggested tools have been standardised and validated and are widely used for systematic review purposes. Each tool will be tested independently by three reviewers, with two full text papers and reviewers will agree the best to work with depending on which tool fits the best with the purpose of this review and offers a good selection to cover the types of methodologies used in each of the included studies. Once the tool has been agreed, the remaining studies will be appraised by one reviewer. Through the critical appraisal of the included studies it may be found that some studies may have some gaps in relation to methodological quality and reporting findings but may still include contextually-rich details that contribute to the overall narrative synthesis and answer our research question.

Findings from included studies will be synthesized narratively. The 'Guidance on the Conduct of Narrative Synthesis in Systematic Reviews' will be used to advise the narrative synthesis [17]. First, a preliminary synthesis will be conducted to develop an initial description of the findings of included records and to organize them so that patterns across records can be identified. In a second step, thematic analysis will be used to analyse the findings. The following five steps of thematic analysis will be followed adopting a recursive process [18]:

- a) Familiarization with the extracted data
- b) Generation of initial codes
- c) Searching for themes
- d) Reviewing themes
- e) Defining and naming themes

### Analysis of subgroups or subsets

not applicable

### Contact details for further information

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### Organisational affiliation of the review

The Open university

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### Type and method of review

Narrative synthesis, Systematic review

### Anticipated or actual start date

05 May 2020

### Anticipated completion date

01 December 2021

### Funding sources/sponsors

none

### Grant number(s)

State the funder, grant or award number and the date of award

### Conflicts of interest

### Language

English

### Country

England

### Stage of review

Review Ongoing

### Subject index terms status

Subject indexing assigned by CRD

### Subject index terms

Acceptance and Commitment Therapy; Adult; Grief; Hospice and Palliative Care Nursing; Humans; Palliative Care; Sexual Partners; Spouses

### Date of registration in PROSPERO

28 July 2020

### Date of first submission

09 June 2020

### Details of any existing review of the same topic by the same authors

### Stage of review at time of this submission

Stage	Started	Completed
Preliminary searches	Yes	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

*The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.*

*The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.*

## Versions

28 July 2020