

What psychological interventions are effective for improving the mental health and wellbeing of adult carers and young carers: A scoping review

Executive Summary

1. There are a variety of psychological interventions evidenced to improve the mental health and wellbeing of adult carers but there is an absence of studies on young carers.
2. Adult carers:
 - a. The combination of psychoeducation with some form of therapy or emotional support has the strongest evidence for improving wellbeing.
 - b. Cognitive behavioural therapy is helpful for clinical outcomes.
 - c. Acceptance and commitment therapy is helpful for clinical outcomes and quality of life.
 - d. Existential therapy likely improves wellbeing.
 - e. Mindfulness/meditation likely improves wellbeing.
 - f. Most evidence shows that support groups significantly improve wellbeing. However, there is some mixed evidence which may indicate they are effective under certain conditions or when delivered to a high standard.
 - g. There is mixed evidence for the effectiveness of counselling.
 - h. This review found that befriending/ peer support on their own do not improve wellbeing outcomes. However, more research may be needed.
 - i. To make conclusions on other psychological interventions, more research is required.
3. Young carers:
 - a. Due to the lack of robust evidence for young carer psychological interventions, no generalisable conclusions can be made. However, qualitative evidence suggests that young carers might benefit from breaks paired with emotional support or hobbies, having someone to talk to, leisure and carer training.
 - b. Young carer cross-sectional evidence suggests social support, benefit finding and relationship quality with the parent (for young carers of parents) are associated with wellbeing outcomes.

Background

Although caring can lead to positive impacts such as feelings of gratification and growth (17) and increased compassion (7), one in five unpaid carers report low mental health in the UK (50), and two in three report feeling lonely (48). Young carers are 3.7 times more likely to be depressed than non-carers (6) and UK longitudinal evidence indicates young carers are more likely to report psychological distress and self-harm (27). Additionally, a UK national survey found that wellbeing was carers' most important need (9). The Informal Caregiving Integrated model indicates that these outcomes are determined by both environmental influences and the caregiver's psychological characteristics. To what extent both of these have negative impacts on the carer, can potentially be altered by psychological interventions (20).

Despite this, direct support for carers from local authorities in England has reduced over time by 13% from 2018 to 2023 (47). This is even with an increase in the intensity of caring from 2011 to 2021 (49).

Aim of Review

The aim of this review is to identify which psychological interventions improve the mental health or wellbeing of unpaid carers, looking separately at adult carers and young carers. This is with a view to make programmes and policy work, delivered by Carers Trust and its local carer services more evidence informed to ensure they demonstrate social impact, as well as to share this evidence with relevant stakeholders external to Carers Trust. The ultimate aim is to enable unpaid carers to enjoy a fulfilling life alongside their caring role.

Evidence Summary

Adult Carer Psychological Interventions

Psychoeducation¹

The bulk of research on psychological interventions is on psychoeducation. However, most findings show that delivering psychoeducation on its own, without any other intervention is not effective at improving depression, anxiety and other wellbeing outcomes (3, 24, 22, 60) but may help with care recipient symptom management and stress-management (24, 25). It is suggested that psychoeducation may be best delivered as part of a package of care (3).

Psychoeducation paired with psychotherapeutic interventions

There is considerable evidence that multiple interventions being delivered concurrently are the most beneficial for unpaid carers (10, 11, 3, 18). Most evidence supports psychoeducation paired with therapy or emotional support. This has helped improve distress (10), depression (46), anxiety, overall wellbeing (54) and quality of life (37). However, one randomised control trial which used counselling as emotional support found it did not help with carer depression, stress, perception of criticism or emotional over-involvement (5).

¹ Psychoeducation is a therapeutic service which provides information to someone with a mental illness, a carer(s) or family member(s), on the illness they have or how to cope with that illness.

Cognitive behavioural therapy (CBT)²

One systematic review found CBT interventions had the most beneficial results compared to other psychological interventions, especially for reducing depressive symptoms (64). Two studies found that reduced dysfunctional thought may have been a large contributor to these reduced symptoms (22, 56). However, two randomised control trials (RCTs) found CBT did not significantly improve quality of life (43, 56). This may indicate that while CBT affects clinical outcomes, it may not affect more holistic measures of discomfort in daily life.

Acceptance and commitment therapy (ACT)³

The evidence for the effectiveness of ACT for unpaid carer wellbeing is strong. One systematic review and meta-analysis found that ACT improves depressive symptoms and quality of life in particular, but also anxiety and stress (23). Another found it improved these outcomes, as well as guilt, interpersonal problems, positive experience with caregiving and general wellbeing, and for carers of dementia in particular (1). When ACT is delivered online, according to one study, it only made a difference to depression and decreased thought suppression but there was no difference in anxiety or quality of life (33). Previous research suggests that ACT works by increasing psychological flexibility which buffers against psychological distress (1, 23).

Existential therapy⁴

There were two high quality RCTs on existential therapy found in the review. These led to improvements in depression, anxiety, quality of life, life satisfaction, meaning in life and confidence (32, 26). These outcomes may be mediated by levels of mindfulness (32). However, more studies should be conducted to confirm these findings.

Mindfulness and/or meditation

To date the evidence on the effectiveness of mindfulness for unpaid carers is positive (11), specifically for mindfulness-based stress reduction, mindfulness CBT and meditation (44). However, interpretation should be cautious, as the evidence mostly comes from uncontrolled studies and therefore, more high-quality research is needed (44, 35). Despite this, one non-randomised control trial found that meditation led to decreased blood pressure, heart rate and anxiety, and improved happiness (15). Another cross-sectional study found associations between carers' levels of mindfulness, with confidence and depression (25).

Digital Interventions

Research on the effect of psychological interventions delivered online is in its infancy so definitive conclusions are difficult to make. Many studies testing the feasibility of them have positive results (29, 60). In addition, qualitative evidence suggests that a major

² Cognitive behavioural therapy (CBT) is a talking therapy that can help you manage your problems by changing the way you think and behave.

³ Acceptance and commitment therapy (ACT) is a type of therapy which emphasises acceptance to deal with negative feelings or circumstances and encourages increased commitment to activities that uphold your values or goals.

⁴ Existential therapy is a form of psychotherapy that uses theories and practices of philosophy to address the challenges related to being human. Existential therapy helps you identify how you have a personal responsibility for your behaviours.

benefit of digital interventions is that it is flexible and self-paced (60) and provides a sense of empowerment (2). One systematic review however, found that non-digital psychological interventions are more effective for wellbeing and that technology-based interventions had a lack of effect (24). Another systematic review of lower quality studies found positive effects on distress (18). More high quality primary studies investigating the effectiveness of digital interventions are needed (16, 60).

Support groups

Two systematic reviews found that support groups were beneficial for wellbeing (21) and psychological distress (24). One qualitative study found that they provide validation and crucial social support (18). However, one review found that the evidence for support groups was mixed (16) and one found they were ineffective for depression and quality of life (11). Support group effectiveness may be determined by the quality and duration (16). In addition, some researchers use the term "support group" to refer to any intervention that has the potential to provide social support e.g. psychoeducation, family counselling, but may not be the primary aim. Therefore it is difficult to determine if results are due the "support group" element or other aspects of the intervention.

Counselling⁵

One systematic review focused on carers of people living with dementia found that counselling was ineffective at improving depression in three out of four studies, ineffective for quality of life in four out of five studies, ineffective for anxiety in one study and ineffective for stress in three out of three studies (64). Another found that counselling/psychotherapy was beneficial for depression and anxiety (11). However, this review specified that some interventions grouped in the counselling category incorporated aspects of CBT and psychotherapy⁶. This mixed evidence might indicate that counselling based on CBT/psychotherapy principles may be most effective.

Befriending and peer support

One systematic review, focused on carers of people living with dementia, found two studies where befriending and peer support had no significant effects on quality of life, and one study had no effect on anxiety or stress (64). More research is needed in this area.

Paired interventions

Paired interventions offer support to both carer and cared for at the same time. There is a small amount of evidence suggesting they are effective at improving wellbeing of the carer. Evidence exists for targeting communication skills, interpersonal connection, education, self-care (19) and problem solving (37).

⁵ Counselling is a form of talking therapy that involves the counsellor listening to a person's current problems and helping you find ways to process those problems.

⁶ Psychotherapy is similar to counselling but is based off of psychoanalysis principles with a trained therapist and goes deeper to understand unconscious thought processes and long-term difficulties.

Tips from the research for psychological interventions

The following section details how psychological interventions should be delivered, to ensure barriers are reduced and carers get the most out of the intervention. The findings come from a variety of study types, both quantitative and qualitative.

- Ensure interventions are clearly structured and well-designed (16)
- Need to be flexible in the times interventions are delivered (30)
- If delivered via a group, it may be helpful to make sure members of the group have similar needs (30)
- While carers reported wanting individualised interventions (58), evidence indicates the following should be focused on: problem solving (21, 30), coping skills, increasing self-efficacy (10), dealing with guilt, appraisal of cared for symptoms, grief (of cared for), loneliness and financial matters (30)
- Can be delivered by paraprofessionals to lower costs (10) but must have enough knowledge (53)
- Barriers to acceptability of psychological interventions include participants' poor health status, low education levels, caregiver burden, change of intervention leaders (53).

More research is particularly needed on the following interventions:

The following are psychological interventions for which this review either did not have enough evidence to make any conclusion on or included reviews suggested that more research was needed on them.

- Dialectical behavioural therapy
- Compassion-focused therapy
- Befriending and peer support
- Art and music-based therapies
- Leisure activities
- Problem-solving interventions
- Psychotherapy
- Animal-assisted therapies

More research is needed on:

The following are suggestions for further research questions identified as lacking in the literature.

- Cross-cultural research to understand what interventions work for different groups
- What is the ideal duration/ number of sessions for interventions
- What is most cost-effective in the real world
- The understanding of mechanisms; what are the mediators and moderators of outcomes?
- More research on the benefits of whole-family approaches or interventions that help the carer and cared for at the same time

Young Carer Psychological Interventions

The literature search for young carer psychological interventions identified zero RCTs or quasi-experimental designs (QEDs) and mostly qualitative evidence. RCTs and QEDs are particularly important in intervention research because they are able to imply cause and effect between the intervention and outcome(s) and therefore findings are more likely to be replicable. Additionally, most of the research on young carers interventions does not look at specific psychological interventions but at what benefits young carers in general.

Due to the lack of high-quality studies, the following summary of evidence should not be considered definitive or generalisable but starting points to begin the design of services which should be further evaluated.

Qualitative evidence

Breaks and emotional support

The most common intervention reported to benefit young carers across qualitative studies was some form of break together with other emotional support interventions or time provided to spend on their hobbies (8, 38, 45, 51, 59). Breaks helped young carers to relax (55), provided a distraction (13) and alleviated worry (8). One qualitative study interviewing practitioners, strategic leads and young carers found it was important to shift from solely providing respite to developing a whole family approach (42). Providing family mediation or counselling as well may be helpful (45).

Someone to talk to

The next most common intervention reported to benefit young carers was the provision of someone to talk to about feelings and experiences (8, 13, 55). It was important that this person understood the caring role and was patient (61). Two qualitative studies suggested that an adult should be present (8, 61). This could take the form of young carer groups, supervised by an adult, which have helped young carers feel they are not alone in caring (55, 57) and improved the carer relationship with the cared for (34). Moreover, these groups provide young carers with the opportunity to make new friends (42, 57). These groups do not suit everyone though as they can make some feel excluded and anxious (61).

Leisure and hobbies

Young carers also find having the time to spend on leisure and their hobbies is important for their wellbeing (13, 42, 55). These help young carers to create physical and emotional distance from the family situation (13).

Training

Qualitative evidence also suggests that training to help the young carer understand the condition they are caring for would provide benefits (34, 55, 63).

Quantitative cross-sectional evidence

Cross sectional evidence is when researchers look at how one variable increases and looks to see if another variable increases or decreases at the same time. While they can imply a link, they cannot determine any causal relationships.

The first cross-sectional study indicates that social support was the strongest and most consistent predictor of levels of distress, positive affect, and life satisfaction. The coping strategies associated with these outcomes were increased approach coping strategies (problem-solving, seeking support and acceptance) and reduced avoidant coping strategies (wishful thinking and denial) (52).

The second study found that benefit finding⁷ was associated with better wellbeing directly and indirectly by improving subjective coping and in turn lowering helplessness. The study recommended that interventions for carers allow them space to explore both the negative and positive aspects of their caring role. (63)

The third study was cross-sectional and longitudinal. Longitudinal evidence indicated that those who had depression at time point one were five times more likely to be depressed at time point two. This emphasises the importance of early intervention. Cross-sectional evidence indicated that caring for a parent was associated with a higher risk of depression compared to caring for other relatives. Positive relationship quality with the parent was associated with lower depression both cross-sectionally and longitudinally. This emphasizes the importance of whole family approaches (6).

Tips from the research for psychological interventions for young carers:

The following section details how psychological interventions should be delivered, to ensure barriers are reduced and carers get the most out of the intervention.

- Better access to information on available services should be provided, as opportunities are often missed. Although, it should be noted that even with information, access and provision is limited. (8, 13, 45)
- The young carer should be involved in decisions about their own support (8, 39, 63)
- Emphasising the positive impacts of caring is helpful for young carers, helping to improve feelings of pride and self-esteem for helping others (13, 39, 6)
- Young carers should have choice and flexibility in support (8, 61)
- Measures should be taken to prevent the changing of practitioners (61, 63)
- Barriers to young carers accessing support include low standard services (45, 61), stigmatization of illness and caring (12, 45) lack of identification (12) long wait times (61) and transport issues (45)

More research is needed on:

- Feasibility studies of specific psychological interventions for young carers
- High quality RCTs or quasi-experimental designs on specific psychological interventions to improve young carer wellbeing.

Limitations

This review has a number of limitations that should be noted. First, this was not a full systematic review so therefore does not capture all the literature that exists on this topic. This could mean that key studies have been missed. Additionally, a formal quality assessment of each paper was not completed, only the study designs were noted.

⁷ Benefit finding refers to an individual's perceptions that they have derived some positive effects from challenging experiences

Therefore, while lower quality designs have been given less weight, the included RCTs and QEDs may have other aspects of their design that are flawed but have not been considered.

Due to limitations in resource, this review did not look at how interventions affect different demographic characteristics which further research should investigate. Additionally, some interventions were limited in the outcomes they measured. Depression and anxiety are often focused on but we may find different results for other neglected outcomes. Finally, this review defined effective interventions as those that improve carer mental health or wellbeing but it may be that for many carers, interventions that keep their mental health or wellbeing at the same level can be considered successful. Future qualitative studies should investigate the importance of this for carers.

Conclusion and Recommendations

Broadly, the evidence presented in this review suggests there are different psychological interventions that can help different outcomes for adult carers but that there is more research needed on young carer psychological interventions. For adult carers, the best evidence is for using a combination of psychoeducation and an emotional support intervention. CBT is more likely to help clinical outcomes, while ACT and existential therapy may help more global outcomes like quality of life. The mixed evidence for support groups and counselling may suggest they are only effective when delivered under certain conditions or to a high quality. There was no support found for befriending/peer support being effective, however, more research with a wider search of literature is needed on this. More research could be done on other psychological interventions for carers.

For young carers, there were no high-quality quantitative studies but qualitative evidence pointed to the importance of providing the young carer with a break, while also providing emotional support. Having someone to talk to, time spent on hobbies/leisure and carer training may also be beneficial. In cross-sectional evidence, the importance of social support, whole family approaches and benefit finding was emphasized.

Recommendations:

- Access to more holistic care for adult carers should increase, combining elements of psychoeducation and emotional support or therapy.
- Therapies for adult carers should be chosen based on individual needs and specific outcomes they are hoping for.
- More primary quantitative research of RCTs or QEDs on young carer interventions should be conducted.
- There should be increased funding and access to formal mental health support for young carers, ensuring they all have someone they can talk to and can get breaks and time for leisure.
- Local governments and health and social care who have plans to improve the mental health of the UK population should have specific plans for how to help unpaid carer mental health. These plans should be collaborative with local carer services so that there are no gaps in provision across the country.

Methodology

A search of online databases (Medline, Google Scholar) was conducted using a comprehensive list of key words and boolean operators. All study types were included, as well as reviews. The first 50 results from each database, for both adult carers and young carers were retrieved and screened for inclusion. This amounted to 200 studies. All of these were peer-reviewed and there was no grey literature. Data was then extracted into two predesigned excel tables. Papers using less robust study designs or those that only had one study evidencing an intervention were given less weight (30, 40, 31, 41, 36, 37).

Due to a lack of results from the initial search on young carer interventions, citation lists were used to source more evidence. 56 papers were in the end included.

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