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APPLICATION AND EFFECTIVENESS OF COGNITIVE BEHAVIOURAL THERAPY AMONG INFORMAL CAREGIVERS OF CHRONICALLY ILL PEOPLE – LITERATURE REVIEW

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Summary

Caring for a chronically ill person is a crisis experience for caregiver, who in specialist literature are called informal carers (ICs). The consequences of informal care are associated with both physical and mental health disorders – including symptoms of depression, anxiety, distress or stress.

Existing research documents the application of cognitive-behavioural therapy (Cognitive-behavioural therapy, CBT) as an effective intervention for ICs, however, the efficacy of CBT methods varies across different informal caregivers groups.

The purpose of this article is to present the overview and effectiveness of CBT methods for ICs of chronically ill patients, discussing the main theoretical concepts of this approach, general goals and therapeutic methods. Finally, the effectiveness of the treatments as well as limitations of the studies are discussed.

Cognitive – behavioural therapy is an effective method of working with neurocognitive patients' informal caregivers, it has diverse and flexible therapeutic protocols that allow the goals of therapy to be tailored to the needs of the caregiver. Given the challenges of an aging population and the prevalence of chronic diseases, informal care is becoming a significant challenge for the healthcare system and will require the attention of mental health professionals.

Methods

The aim of this article is to present an overview of research on the methods and effectiveness of cognitive behavioural therapy among caregivers of chronically ill patients. The following study is a literature analysis covering articles from 2015-2021, which were found using the PsychINFO, PubMed, PMC databases on the basis of keywords appearing in the titles and abstracts: "CBT & informal caregiving", "CBT efficacy & informal caregiving", Informal caregiving & Cancer & Dementia & CBT ". Works in which therapeutic methods were not described in the CBT were excluded, as well when the language was different than English. A total of 19 papers were found on informal care and cognitive-behavioural or third wave therapy, including meta-analyzes, systematic reviews and original papers.

Caregiving as a source of stress for family members

Caring for a chronically ill person is a difficult and burdening experience for family members who, as a result, often require specialist help themselves [1]. The consequences of caring have been studied among relatives of people who suffer from different types of dementia, for example Alzheimer's or Parkinson's disease [2]. Currently, the care burden is studied for various groups, including family members of cancer patients, the elderly or people with mental disorders [3-5]. In the literature, family members are called informal carers, family carers or closest relatives [6-7]. An informal carer (IC) is a person who nurses a relative or a friend, child or adult for free [8]. This group includes the closest family members – spouses, children, parents, more distant relatives or unrelated people [9]. It is estimated that around 80% of long-term care is provided by informal carers [10]. Research indicates that as much as 34.3% of the population looks after a dependent person, and 7.6% qualify as intensive carers, i.e. caregivers for at least 11 hours a week [11].

The role of a carer comprises direct and indirect care as well as managing other responsibilities [12]. The tasks of ICs include: those associated with the illness – for example, coping with symptoms, performing medical procedures, taking the patient to hospital, assisting in hygiene or providing emotional support for the patient or other family members; practical – connected with household duties or finances; spiritual – accepting loved one's limitations caused loved by illness and dealing with the possibility of him/her passing away; social – work, relationships with others [13-14]. In addition, family members must balance changing roles – caregiver and partner or child, or taking care of themselves and their loved ones [15].

Most informal caregivers are not professionally prepared to perform specialised care-related activities as well as managing other activities, although it should be emphasised that the experience of care is not the same in different IC groups. The differentiating factors include: type and severity of the illness, the duration of care and the resulting restrictions in the life of the caregiver, as well as external factors for example in the form of availability of social support, and internal ones, like the ability to cope with stress [16-18]. Despite these differences, the consequences of caring for a chronically ill person seem universal. Although there are reports of benefits associated with caregiving [19], ICs are characterised by an increased sense of distress and burden, with a small amount of social and professional support [7].

The consequences of caregiving for chronically ill person

The problems most frequently reported by ICs include: elevated anxiety, low mood, low energy, insomnia, appetite disorders, stress, negative affect, a sense of social isolation, a lack of interest in previous activities and a sense of lack of time for oneself [20]. These difficulties are categorised as depressive and anxiety disorders, physical health problems [21], distress, burden, reduced quality of life and social problems and financial stress [6]. For example, in a meta-analysis conducted by Collins and Kishita [22], it was indicated that in the NO group of demented patients, the prevalence of depressive disorders was 31%, and anxiety disorders were 32% [23]. However, in the group of caregivers of cancer patients, the prevalence of depression ranges from 42% and 46%, respectively [24].

Caregiving is also a risk factor for somatic health issues [25]. Chronically stressed caregivers of patients with dementia were found to have immunological deficits in the form of lower T cell proliferation, increased production of immunoregulatory cytokines and reduced antibody response to vaccination against tuberculosis [26]. These problems are not only directly related to caregiving stress, but also to the individual characteristics of caregivers, which include age, sex, quality of the marital relationship with the patient [29] or the state of mental and somatic health before the diagnosis [24, 27-28]. The coping style, level of mental resilience, sense of control and availability of social support are also mediators in the relationship between care and its negative consequences [29-31]. In addition, stressors such as the patient's behaviour and needs, financial problems or the caregiver's weakening of self-esteem can significantly affect the carer's health and their readiness to take up and maintain the caregiving role [32]. For example, studies on the experience of care during the Covid-19 pandemic indicate a deterioration of mental well-being in the IC's group [33].

To prevent or lessen these negative caregiving effects, both psychoeducational programmes and structured interventions have been developed, aimed at increasing IC's knowledge about the disease and acquiring skills related to caring or taking care of oneself [34]. Among the proposed programmes are some targeted individually to the carer, or to both the caregiver and patient, and also group interventions and online tools [35-37]. The above interventions differ in terms of (1) the offered strategies, for example, interpersonal, existential, cognitive behavioural (CBT) therapies, learning to solve problems, psychoeducation, administering medication, and (2) the purpose of intervention, for example, reducing depressive and anxiety symptoms, increasing the quality of life or IC's self-esteem related to caregiving or learning new skills.

Cognitive Behavioural Therapy as an intervention for informal caregivers

CBT is an effective intervention in the treatment of depression, anxiety disorders and difficulties related to adapting to stressful situations [38]. Some studies also suggest its greater effectiveness compared to other psychosocial interventions [39]. According to the cognitive model, the meaning given to the situation determines the emotional response. The positive or negative effect depends on the adaptive or maladaptive ways of thinking that ultimately condition behaviour [40]. During CBT therapy, the patient gains both cognitive and behavioural skills that help in coping with dysfunctional thoughts and strategies, which, in effect, increase the ability to deal with stressful situations. Considering the effectiveness of CBT in the treatment of anxiety and depressive disorders, it is an intervention often chosen by both researchers and practitioners in the IC population [2].

Aims and methods of CBT for ICs of chronically ill patients

The goal of the cognitive behavioural therapy for ICs is to change dysfunctional thoughts about caring for loved ones and increase pleasant activities [41-42]. Methods include cognitive restructuring, imaginary and in vivo exposure, coping skills training, behavioural activation, behavioural experiments, homework, acceptance techniques, stress management learning, relaxation, mindfulness techniques and counselling how to deal with bereavement [43-44]. The interventions can be carried out directly with the individual, in a group format, or using teletherapy [45-46]. Similarly to traditional cognitive behavioural therapy, CBT for informal carers also relies on protocols that can be dedicated to specific disorders, like depression or anxiety disorders, or being adapted to specific difficulties related to the role of a caregiver.

The protocols consist of different modules, although the decision whether all or some of them should be used depends on the conceptualisation of the caregiver’s problems [47]. A typical protocol includes the following cognitive and behavioural components: psychoeducation about the patient’s disease, explaining the relationship between thoughts, emotions and behaviour and their relationship with the situation of helping, training to recognise and challenge automatic thoughts and dysfunctional assumptions, pleasure planning, learning to take care of oneself [41,43] One study presented in detail a CBT-typical structure of individual sessions, which consisted of examining homework, planning the topic of the meeting and more homework in-between meetings [40]. Fialho [35] also point out home assignments have a strong therapeutic effect for ICs.

The interventions used the result from the case conceptualisation and related to both cognitive and behavioural techniques. The cognitive techniques aim at verifying the perception and beliefs about oneself as a caregiver. Márquez-González [40] propose a protocol in which ICs learn to recognise dysfunctional beliefs and cognitive distortions and to substitute them with more adaptive thoughts. For example, a caregiver who observed the thought: “Only I know how to look after my relatives”, after learning a critical analysis skill of this belief could change it into a more flexible one: “Caring for the sick is teamwork. I can let others help me.” With regard to care, this can mean that beliefs about care, like: “I need to be a perfect caregiver”, “If I am not devoted entirely, it means I am a bad person” are targeted and their rationality is analysed.

Behavioural techniques primarily include increasing pleasurable activities. ICs are taught how to plan pleasures and identify obstacles to their implementation. Depending on the needs, relaxation and assertiveness training, methods to deal with insomnia and social skills training are introduced [40-41,47]. There are also protocols that use the interventions from the third wave of cognitive behavioural therapy [48]. The main techniques include acceptance and commitment therapy (ACT) [49], mindfulness-based cognitive therapy (MBCT) [50] and dialectical behavioural therapy (DBT) [51].

The effectiveness of cognitive behavioural therapy in working with informal carer

Cognitive behavioural therapy is recognised as an effective intervention in counselling depression and anxiety disorders [52]. Research on the effectiveness of CBT among ICs confirms these conclusions, however, this effectiveness depends on the studied population. In the group of carers of people suffering from neurocognitive impairment the effectiveness of CBT is noticeable, whereas in the case of carers of cancer patients, the results are inconclusive [2,48].

A meta-analysis carried out by Kwona [41] shows that after finishing CBT the symptoms of depression, anxiety, distress and the severity of dysfunctional thoughts in the ICs of dementia patients decreased significantly. In addition, factors directly related to care, such as feelings of self-efficacy, dealing with the destructive behaviour of the patient or life satisfaction, improve. A study by Kaddour, Kishita and Schaller [53] indicated that the use of CBT techniques, even of low intensity, reduces anxiety, depressive symptoms, distress and, in a significant way, the feeling of being burdened with care. Also research conducted in the group of carers of people suffering from Parkinson's disease indicates that after an average of fifteen sessions the severity of mental health disorders and stress significantly decreases in this group [48]. Other studies confirm and extend this trend with noticeable changes in the quality of life, a lesser burden as well as positive changes in the coping strategies used by the ICs [35]. Losada [43] show that in the case of depressive disorders CBT is equally effective as ACT, although only in the case of cognitive behavioural therapy does this effect persist also after the end of therapy. However, different results were obtained for anxiety levels where the effect lasted only after using ACT. The authors explain these differences were obtained due to the specificity of the disorder and the strategies used. In the case of depression, CBT seems to be a better option for ICs because of the easier to understand therapy model, while ACT, because of the emphasis on accepting fear, favours its habituation. In summary, the authors indicate that one quarter of dementia caregivers will experience significant improvement thanks to the proposed techniques.

Other results regarding CBT's effectiveness were obtained in the group of cancer caregivers. A meta-analysis by O'Toole [2] indicates that in a half of the 39 studies carried out, at least one positive effect was found, 33% did not find any effect, and 17% of the studies did not find differences due to small groups or methodological limitations. The authors hypothesise that the low effectiveness of CBT may be due to non-compliance with the theoretical assumptions of this approach to the ICs situation. The cognitive behavioural therapy model assumes that negative emotions can result from errors in the way of thinking. For cancer ICs these thoughts may, however, be valid which results in making the caregiver perceive the interventions as devaluing. This lack of clarity in the results for CBT's effectiveness in different populations emphasises the need for careful assessment of the problems and needs of carers, especially in the case of illnesses where there may be rapid changes in the patient's status [54].

When analysing the effects of CBT among informal carers, attention should also be paid to methodological limitations that impede reliable assessment of its effectiveness. In the first place, not all the studies were randomised controlled trials. In addition, the authors do not always specify which therapeutic strategies were used in the study or describe interventions that could qualify as CBT interventions but have a different, non-CBT name [2]. Finally, limitations include small, homogeneous groups, no long-term assessment of the effects and a high attrition rate associated with excessive caregiving duties, problems with time planning or the death of a sick person [37,40].

Conclusions

The purpose of the presented text was to demonstrate the problem of informal care and assess if CBT is an effective method for supporting this group. The results of this review indicate that cognitive-behavioural therapy only answers to problems of certain groups of caregivers. With regard to informal caregivers of cancer patients, the research results do not clearly indicate whether CBT should be the recommended method in working with this group or not. These inaccuracies may result from methodological limitations. Research in larger groups with more stringent operationalization of variables could help answer whom to recommend CBT.

The answer to this question seems to be of utmost value. Caregivers of chronically ill people are at risk of developing mental health and physical disorders, which can affect the quality of their care, and also indirectly affect the patient who may experience increased anxiety, a lowering of the quality of life or exacerbated disease symptoms as a result [37]. Given the challenges of an ageing society and the incidence of chronic diseases, informal care may become relevant to an increasing number of people and develop into a major problem from the health policy perspective. Effective care for the caregiver can, therefore, not only provide relief for the healthcare system but, from the family perspective, both for the caregiver and the patient.

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