

Determinants of the Effect of Existential Behavioral Therapy for Bereaved Partners: A Qualitative Study

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Abstract

Background: Informal caregivers of palliative patients took part in existential behavioral therapy (EBT), a group intervention comprising mindfulness exercises to reduce psychological distress and improve quality of life.

Objectives: This study examined what the participants perceived as helpful to cope with their loss during the first year of bereavement, particularly with regard to the EBT intervention.

Design: Sixteen problem-centered, semi-structured interviews were evaluated with content analysis.

Results: Two main categories were found: social support and self-regulation. Social support includes sense of belonging as well as emotional, cognitive, and practical help experienced from others. Mindfulness and acceptance, a clear focus on the positive, and orientation toward the future were helpful strategies of self-regulation; these were also part of the EBT intervention. Mindfulness was understood as permitting emotions and acceptance of one's inner processes, even if they were not pleasant, and was found to be helpful to stop ruminative thinking.

Conclusions: The categories considered as being helpful parallel core elements of EBT and recent grief theories. The intervention was found to be supportive and met the needs of the participants. The interviewees appreciated the continuity of EBT support from palliative care into bereavement.

Introduction

PARTNERS OF PALLIATIVE PATIENTS are exposed to various stresses: their support of the patients can be extremely burdensome, both mentally and physically, and may cause them to require support themselves. High prevalence of mental disorders has been reported in informal caregivers of palliative patients: according to self-ratings in approximately 20%–30% and in advanced stages of disease up to 30%–50%.^{1,2}

Only few psychosocial interventions for relatives of palliative patients have been developed.^{3–6} Group interventions focus on open discussions or invite speakers to share information but are rarely based on psychotherapeutic support.^{7–10} A Cochrane Review emphasized the need of evidence-based interventions.¹¹ Only 11 randomized controlled trials (RCTs) for relatives of terminally ill patients were identified, 9 of which were aimed directly at the caregivers.¹¹ The methodology of the trials was reported inadequately and only small effects were achieved.

Cognitive behavioral therapies have been developed considerably in recent years: questions of values and meaning, mindfulness and acceptance were integrated in the “third wave” of behavioral therapy.¹² Initial meta-analyses substantiate the effectiveness of these approaches,¹³ even though there has been no application in palliative care yet. In the situation of informal caregivers who are confronted with death, it is particularly meaningful to integrate approaches of existential psychology.¹⁴

We have therefore developed existential behavioral therapy (EBT; the manualized intervention comprises six weekly group meetings with a total of 22 hours) to support informal caregivers of palliative patients in the last stage of life and during acute bereavement:

1. Meeting: to get to know each other, introduction into mindfulness.
2. Meeting: death, bereavement, and mindfulness.
3. Meeting: activating resources and finding meaning
4. Meeting: self-care and stress management

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- 5. Meeting: personal values for (re-)orientation
- 6. Meeting: saying goodbye and new steps.

In EBT, mindfulness is a core element of the intervention. Originating in Buddhist meditation, mindfulness in this context means focusing the attention on the present experience with an nonjudgmental, accepting attitude.¹⁵ Mindfulness practice can help to distance oneself from ruminative thoughts and painful feelings. In EBT, mindfulness was practiced during every session through following one’s breath while noticing and letting go of all thoughts, feelings, and sensations. The participants were given a CD and were encouraged to practice at home formally twice a day for at least 10 minutes as well as informally by mindfully performing daily activities (e.g., brushing teeth, walking, garden work).

In an RCT, EBT showed positive long-term effects on quality of life and psychological stress reduction.¹⁶ One hundred sixty relatives took part in this study (EBT intervention: *n*=81, treatment-as-usual control group: *n*=79). Medium to large effects on anxiety and quality of life were found posttreatment (*p*=0.005); medium effects on depression and quality of life still emerged in the 12-month follow-up (*p*=0.05).

Objective

Following the quantitative evaluation of EBT, we wanted to understand what the participants perceived as helpful to cope with their loss during the first year of bereavement, particularly with regard to the EBT intervention.

Methods

In 2010, interviews were conducted with EBT participants who were former life partners of palliative patients. Of all EBT participants, 79.7% were bereaved before or during the intervention.¹⁶ Prospective interviewees were informed about the purpose of the study by one of the interviewers (M.K./J.B.). All participants gave informed consent prior to the interview. The study was approved by the Research Ethics Committee of the University of Munich.

A schedule was used to conduct the semi-structured interviews to combine a clear focus on the research questions with openness for the interviewees’ perspective, their perceptions, and experiences. A standardized opening question was used to predetermine the focus of the interview and to encourage narratives: “Some time has passed since you have participated in the support group. I am interested in how you experienced the group and how you have been doing since then.” Further questions were asked about daily life, coping with grief, and what was perceived as helpful or not helpful in the intervention, particularly with regard to mindfulness.

All interviews were tape-recorded with the participant’s permission and transcribed verbatim by the interviewers or research assistants.¹⁷ All transcripts were verified for accuracy using the original audio records. All names of persons and places were changed to guarantee anonymity of the participants. Postscripts were written for every interview including main topics, the context of the interview, and nonverbal impressions.

Data Analysis

The interviews were analysed with qualitative content analysis¹⁸ in a mixed inductive-deductive process¹⁹ with a

descriptive and cautiously interpretive approach.²⁰ The software MAXqda (version 10; VERBI GmbH, Berlin, Germany) was used for coding and code retrieval. A provisional start-list of categories was generated from the codings of the first two transcripts (inductive). Subcategories and operational definitions for each category were developed, based on the theoretical background of EBT and general psychological theory (deductive). Subsequently, interviews were coded independently (M.K./J.B.) parallel to further data collection. We worked systematically through the texts, meaning units were labeled with codes. Texts were constantly compared and contrasted; connections were sought. Any relevant meaning unit that could not be categorized with the initial coding scheme was given a new code, and the coding structure was constantly revised. Differences between the two researchers were discussed until a consensus was reached (consensual coding). The coding scheme was validated in qualitative research workshops: in one workshop, 10 participants coded one interview, in another they sorted predefined categories written on cards. Results were compared and integrated into the category system.

Results

Sixteen interviews were conducted with the first EBT participants 1 year after the intervention. Recruitment was stopped after data saturation had been reached. Except for family status (partners only), no other criteria were defined for participants. Five eligible group participants could not be reached or refused participation. Table 1 summarizes the sociodemographic characteristics of the interviewees. All couples were heterosexual, all but one married. Ten (63%) were female, the mean age was 58±10 years (range, 38–78 years), 12 (75%) had lost their partner because of cancer, 2 (12.5%) because of amyotrophic lateral sclerosis (ALS), 1 (6.3%) because of dementia, and 1 (6.3%) because of hypoxic brain damage. Interviews lasted 75±32 minutes (range, 36–150 minutes)

TABLE 1. CHARACTERISTICS OF THE SIXTEEN INTERVIEWS

Interviewee	Interviewer	Age	Gender	Months after end of EBT	Months after death
A	M.K.	69	M	15.2	18.6
B	M.K.	57	F	12.9	18.3
C	M.K.	56	F	18.5	20.5
D	M.K.	68	M	18.4	20.0
E	M.K.	61	F	18.9	20.4
F	M.K.	44	M	15.6	16.6
G	M.K.	58	F	16.1	22.5
H	M.K.	62	M	13.1	11.9
I	J.B.	38	F	13.2	14.9
J	M.K.	54	F	13.2	15.8
K	J.B.	64	M	12.9	18.7
L	J.B.	60	F	13.3	14.2
M	M.K.	78	F	13.4	17.7
N	J.B.	46	F	12.8	17.5
O	M.K.	61	F	13.0	14.8
P	M.K.	55	M	12.4	16.5

EBT, existential behavioral therapy; M, male; F, female.

The qualitative analysis indicated two main categories that were found to be helpful during the grieving process: social support and self-regulation (Fig. 1).

Social Support

This category contains positive aspects of the interaction between people in similar situations.²¹ The phrases “to not be [left] alone” with one’s fate or “not to be left standing by oneself” were frequently used in the interviews. Social support can include different aspects: a sense of belonging as well as emotional, cognitive, and practical help.

Self-disclosure

Many of the respondents described an open, trusting atmosphere, in which they could talk about themselves. Self-disclosure is understood as revealing personal, intimate thoughts and feelings to others.²²

Showing emotions. The intervention was perceived as a safe place in which an open, trusting atmosphere was pro-

vided and in which it was possible to express grief or anger without having to hold back or present oneself in a specific manner: “Everybody has cried at least once. One doesn’t have to hide it, that’s the nice thing. And we shared this with each other.” (L)

Talking about death. For some interviewees it was essential to talk about existential issues, the illness, the deceased and their grief: “I talked about my agony and they told me about theirs [...] It probably did everyone good that they were able to get it out and talk about it.” (M)

The necessity of talking about death did not seem to be satisfied in many of the respondent’s personal lives.

Sense of belonging. A sense of belonging and togetherness is closely connected to group cohesion, understood as a network that evolves between the participants, leading to a feeling of acceptance and affiliation.²³ One participant referred to it as “a string that actually connected all of us with one another from the beginning.” (O) Many of the participants

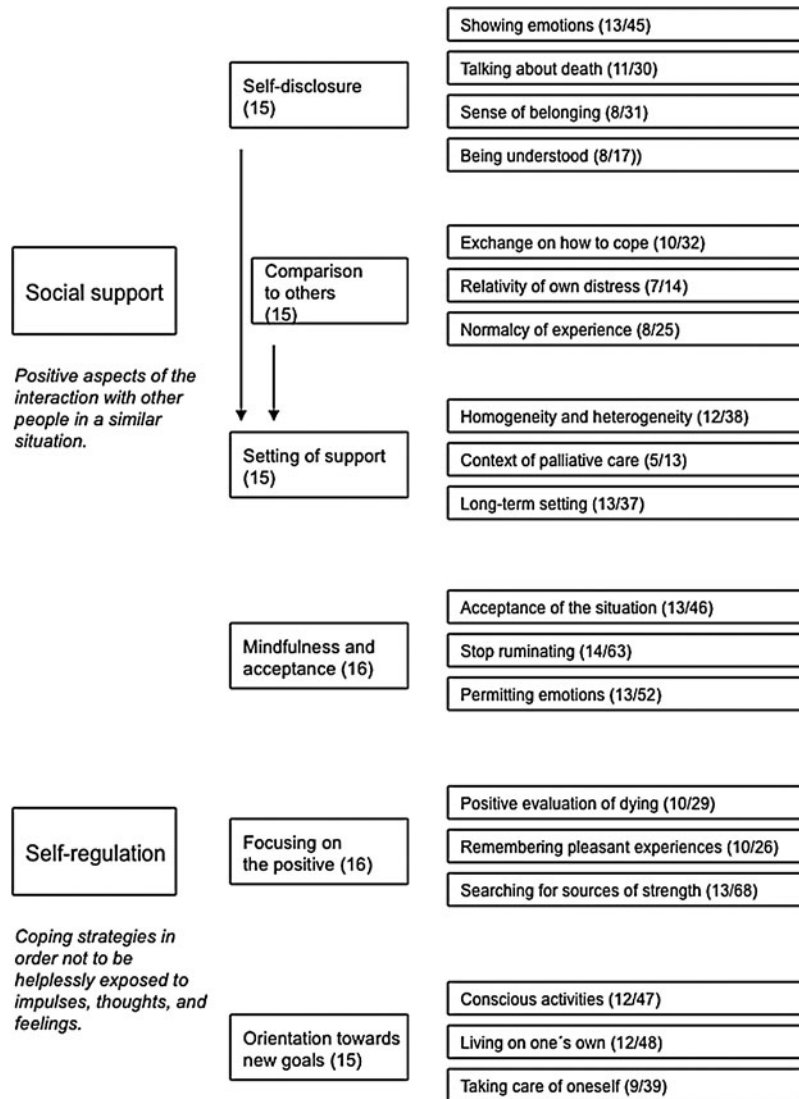


FIG. 1. The first number in the brackets indicates in how many interviews a category was mentioned at least once; the second number shows how often a category was coded in all interviews.

felt as though they were “in good hands” (E, L, O), “integrated” (E, L), and “like someone was there for them” (C, J).

Being understood. Many of the interviewees expressed how important it was for them to be understood by someone who also lost his or her partner: “If this happens to someone personally, they can put themselves into that situation. You don’t need to exchange very many words in that case.” (F)

Comparison to others. The comparison to others encompassed a large portion of the interviews, often also implicitly, as the interviewees often talked about the other participants.

Exchange on how to cope. Many emphasized that they exchanged coping strategies and learned from each other. They talked about how to handle the deceased’s belongings, how to organize Christmas, or how to deal with choosing a tombstone. For others the most important thing was mutual motivation: “I think one notices – well, if she can do it and she can also do it, then I can do it, as well.” (O)

Relativity of own distress. Some interviewees compared themselves to others that were doing worse than or just as bad as they were: “Therefore, I never felt like I was special and that fate is only playing this awful trick on me [...] but to hear about all the terrible things that people of the same age, younger, much younger, or slightly older people have experienced or are experiencing, really helped me. In this sense, it was perhaps a manner of seeing things relatively.” (H)

Normality of experience. Many of the interviewees felt relieved when they found out that others experienced the same thing. They felt like they were normal and not, as was often the case in their everyday life, “exotic or odd” (N). The confirmation of this normalcy affected mainly grieving reactions that were perceived as being inappropriate. Many respondents felt relieved that others also were angry toward the fate or the deceased.

Setting of support

Homogeneity and heterogeneity. Regarding the group’s composition, it seemed that a combination of similarities and differences were viewed as positive by the interviewees in order to learn from each other. “There was a widower in the group. He told us that he had two sons and that he was an electrical engineer, just like me. I listened so attentively because that was me ten years from now, in which the wife’s death would occur ten years later.” (F)

Context of palliative care. It was frequently evaluated positively that the groups were held at the palliative care center: “I actually associate pleasant memories with this house and with this palliative care unit. [...] For me, being a part of and participating in this group of relatives was a continuation of the whole thing.” (G)

Long-term setting. There was a great wish to continue the meetings after the end of the six interventional sessions, to have a “regular, long-term group to exchange experiences.” (I) Many groups continued to meet in a private setting, and

some of them reported that the interaction became even more intense after the “official” intervention.

Self-Regulation

The category self-regulation means what someone does in order to cope with the situation and to not be helplessly exposed to one’s impulses, thoughts, and feelings.²⁴

Mindfulness and acceptance

Mindfulness has been understood as awareness of current experience—feelings, thoughts, and sensations—that includes an accepting attitude.¹⁵

Acceptance of the situation. Acceptance can be defined as an agreement to experience a situation and the willingness, even if it is not pleasant, to permit one’s feelings and thoughts.²⁵ “That has been my experience—the sooner one accepts the situation the way it is and doesn’t ask ‘what if?’ or ‘what would be different?’ the easier it becomes.” (F)

Stop ruminating. Some of the interviewees discussed how important it is to stop repetitive thoughts. Being distracted by watching television, going out, or working was considered helpful. A few explicitly mentioned formal mindfulness exercises: “It is like meditating. [...] And the important thing is not to hold on to these bad thoughts or things, but rather to know that they are there and that that is okay, but that one will get out of this again.” (E)

Some interviewees mentioned that it was helpful to live in the moment. Being aware of nature or the body supported “a conscious perception of ‘what I smell, what I see, what I feel, how I walk, how I breathe.’ That gets me out of this vicious cycle. [...] The hairs on a thistle [...], how these broadleaf trees reflect on the smooth, flat surface of the water.” (N)

Permitting emotions. Many of the interviewees described that it was helpful to permit the coming and going of different emotions that were often caused by memories of the deceased. They consciously exposed themselves to these memories by going to places that they would have gone to together, sorting through the deceased’s belongings, or looking at photographs.

The observation that it helps to let feelings come and go in waves was described by one woman as follows: “I know now that the sadness will go away again and that I do not need to fight it because that is just the way it is. [...] And, I have noticed that if I try to fight it, or would like to push the feeling aside, or would like to deny it [...] I don’t necessarily feel better because of it.” (G)

Focusing on the positive

Some of the interviewees described it helped them to shift their focus onto the positive, in both the past and the present.

Positive evaluation of dying. Some interviewees saw the good parts of the bad: they said that the manner and the time of death were good, dying was a release for the patient, she or he was medically and professionally in good hands. Some even saw that it “was actually also a good time” (C) as their relationship became very deep and they lived more intensively than before.

Remembering pleasant experiences. Interview partners recollected the nice times that they had, what they achieved and built up together. One interviewee said, that if he “wasn’t in a good mood, would then say, STOP!, and try to remember the pleasant things.” (F)

Searching for sources of strength. Many interviewees pictured sources of strength, happiness, and meaning in life. These were particularly experiences with (small) children and grandchildren, in the nature or quiet retreat, connected with spirituality: “The forest means calmness, the forest means smelling, the forest means relaxing, regaining one’s breath, it means wandering, exercise for me, seeing nice things, it gives me something back.” (O)

Orientation toward new goals

For many of the interviewees it was important to deliberately commence a new phase of their life with new activities and an orientation toward their own goals.

Conscious activities. Interviewees consciously undertook activities in order to steer away from the tendency to retract: “And I basically prescribed myself that I need to get out. Not in the sense of running away, but rather in the sense of not barricading myself.” (H)

Many of the participants took on a social task, such as volunteering in a hospice, or were planning on doing so in order to provide meaning for their painful experience.

Living on one’s own. A vital task for many of the participants was to start a new life without their partner. “The time that I spent with my husband is one part of my life and the life that I have now is another part. I had a nice life together with my husband, which lasted 36 years.” (C)

Taking care of oneself. After the death of one’s partner many of the interviewees had more time to notice and take care of their own feelings and needs: “At first you are basically the housewife, mother, and wife, and then you are the nurse, you always have some kind of role to play. [...] With one blow all of these roles get dropped and then, I would say, you get to know your own needs.” (J)

Discussion

The qualitative interviews provide a differentiated overview of factors that bereaved partners who had taken part in a psychotherapeutic support group have experienced as being helpful during the grieving process. The areas considered as being helpful parallel elements that were focused on in the EBT treatment manual. This indicates that EBT may meet the needs of the participants.

Importance of social support

The unspecific factor of social support by others who were experiencing a similar fate was very meaningful to many interviewees, either in its emotional (self-disclosure) or more cognitive and practical aspects (comparison to others). This aspect was addressed in EBT elements that form group cohesion and give open time for exchange. The mutual exchange with people in similar situations was also seen most impor-

tant in other support programs for relatives.⁷⁻¹⁰ This might be partly due to comparisons which help to validate feelings, exhibit better coping strategies and stabilize one’s self-worth.²⁶

Some ambiguity remains regarding the optimal setting for an intervention for relatives of palliative patients, in our study as well as in the literature. On the one hand, homogeneity, e.g., concerning the type of loss, disease of the patient, relationship to the patient, age, is recommended.²⁷ On the other hand, it has been reported that differences in those aspects did not play a significant role.⁹

Evidence on effectiveness of early preventive interventions open to all bereaved is needed.²⁸ It has been reported that bereavement services in palliative care are mainly used in the first 6 months after loss²⁹ with the continuity of prebereavement and bereavement support being emphasized.³⁰ Time-limited support might be a suitable launching for grief-work²⁷ but we found that many partners searched for a long-term setting.

Specific coping strategies

Strategies of self-regulation (mindfulness practice, activating resources, reorientation toward new goals) were main contents of EBT and were also found in the interviews. Several of the interviewees said that it had helped them to know that painful feelings come and go throughout the grieving process. Permitting emotions is highly linked to mindfulness and acceptance-based approaches, in which the inner distance helps to “ride the waves of grief”³¹ as opposed to being overwhelmed by them. Mindfulness-based therapies report similar effects of focusing on the moment, distancing oneself from repetitive thoughts, and dealing with negative feelings.^{32,33}

Focusing on the positive was often used to stop rumination. This is in line with activation of resources and does not contradict the importance of acceptance, as rumination often serves to avoid unpleasant feelings and does not mean active confrontation.³⁴ One year after the intervention, most of the interviewees were moving forward into a new life without the deceased partner. The coping strategies found were similar to other studies: e.g., acceptance of death and orientation toward new goals, considering the future, and continuation of the relationship to the deceased.³⁵ These parallel common grieving tasks: (1) accepting the reality of loss, (2) processing the pain of grief, (3) adjusting to a world without the deceased, and (4) finding an enduring connection with the deceased in the midst of embarking on a new life.³⁶

Limitations and conclusion

A limitation of the study is that the results of this qualitative approach cannot be representative and only elicit experiences from the participant’s view. As the researchers were familiar with the theoretical background of the EBT intervention, a certain terminology is reflected in the categories (e.g., mindfulness). It is difficult to differentiate the contribution of the intervention and other factors within the participant’s life.

In order to perceive a better understanding of the specific impact of the intervention, further interviews with informal caregivers from the control group and those who refused to take part in the trial might be helpful. Exploratory results of a

comparison between participants and nonparticipants indicate that the latter did not mention coping strategies like acceptance that had been facilitated in the EBT intervention.³⁷

More understanding of an optimal setting (e.g., starting point, duration, homogeneity/heterogeneity) and specific contents of support for bereaved partners of palliative patients is needed.

Altogether, the combination of social support and specific psychotherapeutic interventions in the EBT groups seemed to be helpful for partners of palliative patients. Especially mindfulness techniques, resource activation and self-care interventions seemed to be beneficial. The EBT groups filled the gap between palliative care and grief counseling.

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