

Potential utility of bereavement life review for depression and spiritual well-being of bereaved family members in home care: Contents of narratives

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Abstract: The aim of the study was to investigate the potential utility of the Bereavement Life Review as psychological intervention for individuals who provided care for a terminally ill family member and to examine the contents of narratives in the intervention. The participants were 7 bereaved family members who underwent this intervention over two sessions in two weeks and completed the FACIT-Sp and BDI-II questionnaires to measure spiritual well-being and depression, respectively. Contents of narratives were analyzed qualitatively. The FACIT-Sp score significantly increased and the BDI-II score decreased after the intervention. From the narratives, factors such as “*human relationships*” and “*gratitude to others*” were selected as “most important things,” “*characteristics or tastes of the deceased*” and “*memories of trip*” as “memories of the deceased,” “*realization of patient's hopes*” and “*regret*” as “memories of caring at home,” and “*independence and preparation to live alone*” and “*use of experience of home care*” as “changes through experience of caring.” Based on the results, the Bereavement Life Review has the potential to elevate spiritual well-being and alleviate depression.

Keywords: bereaved family, home care, depression, spiritual well-being, life review

Introduction

Bereaved family members may experience physical or psychological problems as a grief reaction (Burnell & Burnell, 1989; Stroebe, Schut, & Stroebe, 2007). Hanson & Stroebe (2007) proposed that grief comprises emotional reactions. About 15% of bereaved persons experience a more problematic grief process with symptoms of depression or posttraumatic stress (Bonanno & Kaltman, 1999). Thus, depression is a serious psychological problem for bereaved family members (Shear, 2009). Some bereaved family members also lose meaning of life or peace of mind because of the loss

of a family member. Such loss of meaning of life or peace of mind is referred to as spiritual pain (Murata & Morita, 2006), and spiritual care is important for these people because spirituality is related to quality of life.

The Bereavement Life Review provides one method of spiritual care. This approach has been shown to be effective for alleviation of depression and elevation of spiritual well-being in bereaved families with a patient who died in a palliative care unit (PCU) (Ando et al., 2010) or in a general hospital (Ando et al., 2014). Life review is also useful for mental health in older community-dwelling women (Binder

Table 1. Background of the participants

ID	Age range of participant	Relationship to the patients	FACIT-Sp Pre	FACIT-Sp Post	BDI-II Pre	BDI-II Post
1	50-59	Child	29	32	2	3
2	60-69	Spouse	32	32	3	1
3	60-69	Child	18	20	3	3
4	30-39	Child	4	8	31	21
5	70-79	Spouse	20	32	4	4
6	60-69	Spouse	27	29	1	7
7	50-59	Spouse	12	24	24	8

et al., 2009). However, it is unclear if this intervention is useful for bereaved families who took care of a dying patient at home. Previous studies have shown that these families may experience burden of care, particularly with regard to the suffering of patients or the practical aspects of care (Ando et al., 2015; Ishii et al., 2012). In addition to these burdens and difficulties, bereaved families have little chance to receive psychological care after a patient has died at home, although some may suffer from psychological problems such as depression or spiritual pain. For this reason, we examined the utility of the Bereavement Life Review for depression and spiritual well-being of bereaved families.

A bereaved family member goes through both positive and negative experiences while caring for a patient (Ando et al., 2014; Kang et al., 2013). However, the views of bereaved families with patients who died at home have not been examined as narratives. Therefore, the goal of this study was to examine the potential of the Bereavement Life Review for elevation of spiritual well-being and alleviation of depression of bereaved family members who took care of a patient at home at the end of life, with qualitative analysis of narratives associated with this intervention.

Methods

Participants

The participants were 7 bereaved family members (Table 1) of cancer patients who required services of a home care clinic, home visit nurses, or a case management agency that provided 24-hour home care services. The inclusion criteria were: 1) the patient had died at least six months ago but not longer than two and a half years ago, 2) the family caregiver and patient were both over 20 years old, 3) the family member was the primary caregiver, and 4) the family caregiver knew about the patient's diagnosis of cancer. Family caregivers with dementia or a mental disorder were excluded from the study. The physician of the hospital chose participants based on these criteria. We first conducted a questionnaire survey and asked participants to attend an interview. If a person expressed intention to participate in the interview, a researcher explained the contents of the study by telephone.

Outcome measurements

The Japanese version of the Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being (FACIT-Sp) scale (Noguchi et al., 2004), which is based on the original version, was used to measure spirituality. Items are scored on a 5-point

scale, ranging from 4 (strongly agree) to 0 (strongly disagree). The Beck Depression Inventory-II (BDI-II) (Beck, Steer, & Brown, 1996) was used to measure the depression of family members. The BDI-II includes 21 items that are scored on a 4-point scale, ranging from 3 (strongly agree) to 0 (strongly disagree). The validity and reliability of the FACIT-Sp and BDI-II are well established. The scores on both scales are presented for each participant in Table 1.

Procedure

After participants agreed to take part in the study, an interview day was determined. Before the interview, a clinical psychologist explained the study to the participant, obtained signed informed consent, and then conducted the intervention. The Bereavement Life Review consisted of two interview sessions. In the first session, the participant reviewed his/her life with a clinical psychologist. Each interview session lasted 30 to 60 minutes and the interval between the first and second sessions was two weeks. The following questions were asked in the first session: (1) What are the most important things in your life? (2) What are your main memories of the deceased when he/she was well? (3) In taking care of the patient, what are your most impressive memories? (4) Were there any changes in you caused by taking care of the patient or by the patient's death? (5) What are your roles in your life? (6) What are you proud of in your life?

The narratives of the participants were recorded. After the first session, the clinical psychologist transcribed the narrative verbatim and made a simple album. In the album, key words from the answer to each question were selected and the therapist pasted photos or drawings from

books or magazines that were related to the participant's words or phrases in order to make the album beautiful and memory-provoking. In the second session, the family member and the clinical psychologist viewed the album together and agreed upon the contents.

The ethical and scientific validity of the study was approved by the institutional review board of St. Mary's College.

Data analysis

Scores on the FACIT-Sp and BDI-II were analyzed by *t*-test. Narratives were evaluated with reference to "Qualitative Analysis" (Funashima, 2001), which is based on the work of Berelson (1952). Narratives were selected from each question. These narratives were separated into the shortest sentence with a meaning, and similar short sentences were integrated into a code. Similar codes were integrated into a sub-category, and lastly, similar sub-categories were integrated into a category. To maintain reliability, this categorization (including the coding) was validated independently by two co-researchers. Inconsistencies were discussed until agreement was reached with the help of a professional in this area.

Results

The backgrounds of participants related to the level of required care, support from others, mental state as a caregiver, and status at the time of the review are shown in Table 2. Categories such as "little" "much" "too much" or "poor" were estimated from the narratives by participants.

The FACIT-Sp score significantly increased from 19.1 ± 9.1 to 25.1 ± 9.0 ($p < .05$, $t = -3.31$) after the Bereavement Life Review, while the BDI-II score decreased from 9.7 ± 11.5

Table 2. Status of caregivers: Categories such as “little” “much” “too much” or “poor” were estimated from the narratives by participants.

	Level of care needed	Support from others	Mental status of caregiver in caring	Status at review
ID#1	Little	Much: Received support from many relatives. Took care of her mother and children with pleasure.	Good:	Satisfaction: Reviewed memories with pleasure.
ID#2	Little	Much: Received support from many persons.	Good:	Satisfaction: Satisfied with her care after husband's death.
ID#3	Much	Little: Gave care only with hospital staff.	Not so good: Was busy since she took care of her father and her children.	Satisfaction: Felt attainment in giving care. Found the next role after his death.
ID#4	Too much	Poor: No support from other family members. Medical staff also relied on her.	Very bad: Worked in a hospital in the day as a nurse and took care of her father at night.	Sadness: After his death, she became depressed. <i>S e e m e d t o</i> experience catharsis through review.
ID#5	Much: Not used to taking care of the patient.	Little: Gave care only with hospital staff.	Tired: Daughter came back with grandchildren. Had to care for all family members.	Positive: Review of taking care produced some good memories.
ID#6	Little:	Much: Received support from her son.	Good:	Positive: Had regrets, but found interests, enjoyment, and a future role.
ID#7	Much: Not used to giving care.	Little: Gave care only with hospital staff.	Not so good: Her husband was angry with her caring methods.	Satisfaction: Recognized that she took care with her strength and accepted herself.

to 6.1 ± 6.9 ($p > .05$, $t = 1.7$), although this change was not significant.

Categories selected from narratives are shown in Table 3. In this paragraph, we show categories with numbers (*No.*), as in Table 3. Response categories to question (1) “most important things” included “*human relationships (No.1)*,” “*growth of children and grandchildren (No.2)*,” and so on; those to question (2) “memories of the deceased” included “*characteristics or tastes of the deceased (No.6)*,” “*memories of trip (No.7)*,” and so on; those to question (3) “memories of caring at home”

included “*realization of the patient's hopes (No.9)*,” “*expected grief for loss (No.10)*,” and so on; those to question (4) “changes through experience of caring” included “*appreciation to others (No.15)*,” “*independence and preparation to live alone (No.16)*,” and so on ; those to question (5) “roles in your life” included “*taking care of parents (No.20)*,” “*being well myself (No.21)*” and so on; and those to question (6) “pride in your life” included “*caring until the last moment (No.23)*” and “*feeling happy about everything (No.24)*.”

Table 3. Categories from narratives by content analysis in the Bereavement Life Review

Question	Category	Sub-category
1. Most important things	1) human relationships	• friends, human relations
	2) growth of children and grandchildren	• children, grandchildren • raising children
	3) making maximum effort	• no regrets • maximum effort
	4) gratitude to others	• gratitude
	5) rich emotion	• being affected by others • being affected by myself
2. Memories of the deceased	6) characteristics or tastes of the deceased	• favorite food, tastes • characteristics of the deceased
	7) memories of trip	• short time for sharing • gratitude of sharing • trip with recognition of death
	8) positive recognition of work	• work for the family • respect from persons in <u>company</u>
3. Memories of caring at home	9) realization of the patient's hopes	• priority to patients' hopes • expectation for family
	10) expected grief for loss	• bathing with family
	11) good memories of parting	• not depressed about <u>prospect of death</u>
	12) regret	• time to move to home care • being alone at the last moment
	13) disagreement about care among family members	• not hoping for home care • conceal disease state from the patient
14) caring alone	• dependent on family • dependent on nurses	
4. Changes through experience of caring	15) appreciation to others	• expression of gratitude from patients • gratitude as a career
	16) independence and preparation to live alone	• trying to be independent • preparation for my terminal stage
	17) knowing families' pain in caring	• knowing others' pain • knowing families' feelings
	18) use of experience of home care	• reflection <u>on</u> lack of care and learning • learning how to care
	19) recognition of care by medical staff	• support of families by staff
5. Roles in your life	20) taking care of parents	• taking care of a <u>single</u> parent
	21) being well myself	• not a burden to others • being well
	22) raising children	• taking care of children • taking care of <u>children's</u> health
6. Pride in your life	23) caring until the last moment	• burden of taking care • strong desire to care
	24) feeling happy about everything	• feeling happy about everything • gratitude

Most of the categories were positive, but one (ID#4) of the 7 participants felt that her experience of caring was negative. She also became depressed after her father died. It may be useful for clinical psychologists to consider appropriate care for this kind of patient, and thus we describe this case in detail.

Case report

The participant (ID#4) was a 30-year-old woman. She was not married and worked as a nurse. Her father suffered from bad health but had not seen a doctor. When he finally consulted a doctor, he was diagnosed with advanced-stage cancer. She decided to take care of him at home, because he wanted to spend the remaining time of his life in

a terminal stage at home. The participant had a mother and a brother; however, her mother did not agree with home care, and her brother worked in another region and entrusted nursing care to her. She provided home care with help from a visiting nurse and doctor. She felt burdened by caring for her father alone. She worked during the day as a nurse and took care of her father at night. The double duty left her exhausted, but she continued to offer care until her father died. From the day he died, she could not sleep and became depressed. She eventually changed her work place. After 12 months had passed, she expressed her intention to participate in this study because she wanted to tell her story. Her pre-intervention BDI-II score was very high and her FACIT-Sp score was low; however, post-intervention, her BDI-II score decreased and her FACIT-Sp score increased.

Discussion

Utility of the Bereavement Life Review

The significant increase in FACIT-Sp score suggests that the Bereavement Life Review can elevate spiritual well-being of family members involved in home care. In a previous study, the FACIT-Sp score of bereaved family members with patients who died in general hospitals (Ando et al., 2014) changed from 24.3 to 25.9 after the intervention, whereas in the current study, this score changed from 19.1 to 25.1. The high pre-intervention FACIT-Sp score of the previous study may have been due to the participants being members of a support group for grief care, with the male participants particularly finding new meaning in the support group. In contrast, the participants in the current

study did not receive this kind of support. However, the increase in post-intervention FACIT-Sp score to the same level as in the earlier study indicates the utility of the Bereavement Life Review for elevation of spiritual well-being.

The average BDI-II score decreased from 9.7 to 6.1, although this change was not significant. Since the cutoff for clinical depression is over 17 points, the participants were not depressed at baseline totally. The BDI-II score in the general hospital study (Ando et al., 2014) changed from 14.4 to 11.6, which indicates that the depression level in the home care study was lower at baseline, compared to participants with patients in general hospitals. This difference may be due to bereaved family members being satisfied with home care, with most not feeling sadness or confusion. In contrast, the female bereaved family members in the general hospital study suffered from sadness and confusion after their husbands' death. Thus, with the exception of subject ID#4, bereaved family members who provided home care were less depressed than those with a patient who died in a general hospital. In the categories selected from the narratives, family members who gave home care narrated positive memories such as "*memories of trip (No.7)*," "*realization of the patient's hopes (No.9)*," and "*good memories of parting (No.11)*." They seem to be satisfied with home care, which might have alleviated depression.

Comparison of categories with previous studies

In the current study, most of the categories were positive, including "*taking care of parents (No.20)*," "*raising children (No.22)*," and "*caring until the last moment (No.23)*" but a few were

negative, including “*disagreement about care among family members (No.13)*” and “*caring alone (No.14)*.”

First, we compared categories in the current study with those identified for caring in a PCU (Ando et al., 2011) and general hospital (Ando et al., 2014). There were 21 participants in the PCU study with a mean age of 65 years. The results from the three studies should be comparable because the time after death was about 2 years in each study and the relationships to the deceased were almost all spouses or children.

Categories such as “*human relationships (No.1)*,” “*appreciation to others (No.15)*,” and “*gratitude to others (No.4)*” were selected by bereaved families in home care. These factors were also selected by bereaved families in PCUs or general hospitals. Common to bereaved family members was that they all recognized human relationships as most important because they were helped by other people after the patient’s death and felt appreciation or gratitude to others.

In contrast, “*healing process*,” “*relationships with society*,” and “*performance of new family roles*” appeared only for participants in the PCU and general hospital studies. This may be because family members in home care performed new roles from a very early stage, which was not perceived as a big change. They also lived in the community and most of their neighbors knew that they were taking care of a patient at home, and thus the participants did not consider a new relationship with society. In addition, they had ample time to witness the changes in the patient, feel the expectancy of death, and finally accept the death of the patient; thus, they did not experience a particular healing process.

Review of Case ID#4

Participant ID#4 in the current study had a very high depression score. Her mother, the spouse of the patient, did not agree with home care, but the participant wanted to realize her father’s hope to spend his remaining time at home. This issue is included in the category of “*disagreement about care among family members (No.13)*.” Furthermore, her mother was afraid of seeing her weak husband and did not take care of him. Hospital staff entrusted nursing care to ID#4 because she was a nurse. This issue is included in the category of “*caring alone (No.14)*.” This case indicates that the level of required care, support from others, and the caregiver’s mental state in providing care need to be considered (Table 2). The high level of care required from ID#4 resulted in her depression. Thus, although there are many good aspects to home care, the burden of caregivers must be considered, and Japanese people may find it hard to see suffering of patients (Kitayama, 1993).

What effect did Bereavement Life Review have on participant ID#4? She had joined this study by chance and received the intervention. Bonding (Bowlby, 1980) to the deceased was strong and the review of various emotions may be helpful to allow her to let go of the deceased. Generally, reviewing or telling a depressing story about a patient has been suggested to promote symptoms; however, in this case, this process did not promote depression but rather allowed the participant to express her feelings. Thus, the Bereavement Life Review may be helpful to allow family members to let go of the deceased.

Role of clinical psychologists

Clinical psychologists function in various

fields, but few are involved in the treatment of bereaved family members who have been taking care of patients at home. However, the high BDI-II scores in some of the participants of this study suggest that family caretakers have a need for psychological care. From this study, we identified three points for consideration by a psychologist with regard to home care: 1) The mental state of a family member during caring for a patient and of the burden of care should be assessed. 2) As for grief care, the Bereavement Life Review may be useful for a bereaved family member at the normal mental health level. 3) When a bereaved family member is depressed, a clinical psychologist can provide support in collaboration with other medical staffs.

Limitations and future research

This study is limited by the small number of participants, which makes it difficult to generalize the results. A future study with more subjects is required to validate the utility of the Bereavement Life Review for bereaved family members with patients who died at home. Moreover, the FACIT-Sp scale was developed to assess spirituality for patients with chronic illness; thus, strictly, we cannot measure spirituality of bereaved family members using this scale. A scale for measurement of spirituality in this population needs to be developed.

Terminally ill patients are currently advised to spend their final time at home, with promotion of home care from hospice physicians and nurses. When patients are in a hospital, family members may have the opportunity to receive psychotherapy from clinical psychologists. However, there are fewer opportunities for receiving psychotherapy when patients are cared for at home and even fewer chances after the patients' death. Thus, in the future, we plan

to conduct the Bereavement Life Review for bereaved families in home care settings to confirm the efficacy of this approach and promote its use as regular psychological care.

"I especially thanks to participants and Dr. Yasuyoshi Ninosaka and medical staffs in Ninosaka Clinic at heart."

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(Accepted April 2, 2015)