

Research Article

Feasibility and Efficacy of Narrative Approach for Spiritual Well-Being of Terminally Ill Patients at Home Hospice

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Keywords

- Narrative approach
- Terminally ill cancer patients
- Home hospice
- Psychological positive aspect

Abstract

The primary aim of the study was to investigate the feasibility of the narrative approach for terminally ill patients at home hospice. The secondary aim was to examine the efficacy of the narrative approach on spiritual well-being, physical condition, life satisfaction, and hope. Twelve patients agreed to participate in the research, in which patients narrated their thinking or feeling along with some questions in two sessions of approximately 60 minutes each. The patients completed the Functional Assessment Chronic Illness-Spiritual (FACIT-Sp) and the FACT-physical, the Life Satisfaction scale, and the Hope scale. The results showed that 1) 10 patients completed the narrative approach (feasibility rate 83%), 2) the FACIT-Sp and the Hope score increased, the FACT-physical decreased, and the Life Satisfaction score did not change, although there was no statistical significance. The FACIT-Sp score was at the same level of the standard score and the Life Satisfaction score was higher than the standard score. These facts suggest that the narrative approach for terminally ill patients at home hospice may be feasible, and it may improve spiritual well-being, physical status, and hope.

INTRODUCTION

Cancer patients experience various psychological distresses like depression [1]. They sometimes lose the meaning of life and peace of mind, which is referred to as spiritual pain or psycho-existential suffering. One of the origins of this pain is the perceived loss of a future [2]. Also, they may lose hope for the future and have low life satisfaction. Thus, support that allows patients to find a source of a future beyond death may alleviate their suffering.

There are some interventions for alleviating patients' suffering. Cognitive behavioral therapy had an effect on anxiety but no effect was observed on depression [3]. Although Dignity therapy was effective, it was found to have no effect on depression measured by their hospital anxiety and depression [4]. Meaning-centered group psychotherapy has been found to improve psychological well-being in advanced cancer patients [5], however, it might be difficult for terminally ill patients to participate in a group therapy.

Life review interview was also a useful intervention used

to promote psychological distress and spiritual well-being for terminally ill patients. This approach helps individuals integrate memories into a meaningful whole and to obtain a harmonious view of the past, present and future [6]. In the Life review interview participants examine how their memories contribute to the meaning of their life, and they may work at coping with more difficult memories [7]. It was shown to be effective for spiritual well-being or psychological distress like depression or anxiety [8]. However, some of the patients would not like to remember their lives or memories. It may happen that participants do not want to integrate their lives and have stress due to the review of their lives in a clinical situation. Thus we needed to develop another intervention for these participants.

Narrative therapy is another useful intervention. Michael White and Epston demonstrated narrative therapy [9]. It comes from social constructivism and the meaning in the context is found in the narrative of the person with the interviewer in an interactive way. Noble & Jones [10], demonstrated the benefit of narrative therapy such that narrative therapeutic approaches allow the patients and the family to tell their stories and find

meaning in them to allow a state of acceptance and comfort. It has been reported that “narrative therapy as an intervention makes an important contribution to the holistic support of the dying patient and his or her family’s with a number of therapeutic benefits [10,11].” Narrative research methods invite people to talk, or write, about their experiences in a naturalistic storytelling style [12].

Most of the previous studies about narrative therapy are qualitative research and not quantitative research. In these conditions, as a quantitative research, Loyd-Williams et al. [13], conducted narrative intervention for patients using palliative care in a hospice day care. Patients receiving intervention had a greater reduction in their depression scale at a six week follow-up, and their median survival was longer than with usual care. Wise et al. [14], conducted a narrative intervention for advanced cancer patients, and suggested that telephone-based narrative interventions hold promise in improving advanced cancer patients’ well-being.

Moreover, these mental or psychological interventions have been proposed in a palliative or hospice ward in hospitals, however, there are very few for terminally ill patients in home hospice. Recently the number of elderly individuals is increasing worldwide; home hospice is one of the most capable choices at the end of life. To develop a new intervention for patients at home hospice, we examined the feasibility of the narrative approach on the spiritual well-being, physical aspect, life satisfaction, and hope of terminally ill patients at home hospice. In this study, we use the word “narrative therapy” in a clinical situation, since this is research we use the word “narrative approach.”

METHODS

Design

To get evidence of feasibility and efficacy, we used a quantitative method using scales. To understand patients’ thinking and feeling, we used a qualitative method of interview.

Participants

We recruited 12 patients, two withdrew, and 10 participated. The participants were 10 patients in three clinic in western Japan. The mean age was 68.9 years old. The participants had various primary diseases, and a Performance Status (PS) [15], from 2 to 4. The stage of disease for each patient was “4” or recurrence. The inclusion criteria were terminally ill patients who used home hospice and were aged ≥20 years old. The exclusion criteria were patients with cognitive impairment or serious mental illness.

Questionnaires

The reliability and validity were confirmed in each study.

1) The FACIT-Sp (Functional Assessment Chronic Illness Therapy-spiritual) scale [16,17] was used to measure spiritual well-being. A high FACIT-Sp score indicates a high spiritual well-being. It includes 12 questions measured from 0 to 4 points. The Cronbach’s coefficient was from 0.81- to 0.91.

2) The FACT-physical in the FACT-G (Functional assessment of Cancer Therapy General) was used to measure physical status from 0 to 4 points [18]. A high score means a high level of physical symptoms.

3) We used the Life Satisfaction scale [19,20], which included

Table 1: The Basic demographic data.

ID	Age	Gender	Stage	PS	Family	Primary site
1	60	M	Recurrence	3	Y	Lung
2	70	M	Recurrence	3	N	Liver
3	70	M	Recurrence	4	Y	Rectal
4	60	M	4	4	Y	ATL
5	50	M	4	2	Y	Lung
6	40	F	4	2	Y	Cervix
7	70	M	4	3	Y	Stomach
8	90	F	Terminal	2	Y	Heart Failure
9	80	M	Recurrence	2	Y	Stomach
10	62	M	4	2	Y	Pancreas

Stage: Disease classification. 4Cancer disease classification stage 4; Family: “Y”=with, “N”=without

Table 2: Mean pre- and post-intervention scores for each scale.

Scale	Pre	Post	P
FACIT-Sp	32.2 (9.7)	33.3 (10.8)	P=0.67
Physical (FACT)	13.7 (7.6)	11.5 (5.5)	P=0.29
Life Satisfaction	22.3 (8.2)	22.8 (8.7)	P=0.57
Hope	15 (3.6)	16.3 (4.4)	P=0.37

P values calculated by Wilcoxon sign-rank test

five question items measured from 1 to 7. The Cronbach coefficient of this scale was from 0.84-0.90. We used the three hope question items from the Comprehensive Quality of Life outcome (CoQoLo) scale [21], we called it the Hope scale in this study. The total Cronbach coefficient of the CoQoLo scale was 0.90.

Procedure

The primary physician introduced the study to a patient who met the inclusion criteria. Patients who showed interest were registered and the researchers sent a letter about the research. After sending a letter, the researcher explained the details of the study to the candidate by telephone. If he agreed to participate in it, they decided the place and time to interview. The interviewer visited the patient's home or a clinic, explained the research again, and received informed consent after agreement for participation.

In the narrative approach, there were two sessions. The first session contained the following questions, 1) How did you live before your illness? 2) How did you live after getting your illness? 3) What are difficulties in your life with in home hospice, and how do you cope with them? 4) What are good things in your life with in home hospice? The second session consisted of the following, 5) What changed after getting your illness? 6) What are the most important things in your life? 7) What is your hope for the future? and 8) How do you think of your life? Getting participants' permission, their narrative was recorded on IC recorders. Before the first session and after the second session, the participants completed the questionnaires. Each session lasted approximately 60 minutes. This study was approved by the ethical boards of St. Mary's College.

RESULTS

We conducted this research at three facilities in Western Japan. A primary physician in each facility contacted the patients. In total 12 patients agreed with participating, two patients withdrew at a later time because their physical conditions decreased and 10 completed the study. The demographic data was shown in Table (1). The rate of feasibility was 83%.

Although there was no statistical significance with each scale score between pre and post, some changes are observed (Table 2). The mean FACIT-Sp score increased from 32.2 to 33.3, indicating an increase of spiritual well-being. The FACT-physical score decreased from 13.7 to 11.5, indicating a decrease of their physical symptoms. The Life Satisfaction score did not change from 22.3 to 22.8. The Hope score increased from 15.0 to 16.3, indicating an increase in the feeling of hope.

DISCUSSION

The feasibility rate for completion of the narrative approach was 83 %. The rate over 80% are similar to previous studies [8,22], and suggests appropriate feasibility. This may be because patients were able to narrate their lives without limitation of their past such as in the Life Review interview. Patients who had bitter memories in old times, were not required to look back on bitter memories. In the narrative approach, they can talk freely and safely without focusing on any traumatic memories.

About FACIT-Sp, the mean score was 32.2 points before the

intervention, and 33.3 after. It is the same as the previous study at 32.0 points in which the scale was standardized for outpatients under medical treatments [17]. That is, the spiritual well-being of patients at home hospice was kept at the standard level. As the score increased a little after the intervention, to 33.3 points, this approach might contribute to increased spiritual well-being. Patients might have found meaning in their lives and felt peace of mind in narrating to the interviewer. The reason why there was no statistical significance consists of the following. Since previous studies showed effects of the narrative intervention after a six week follow-up [13] or four months later [14] for advanced cancer patients, more intervention times may be required to show significant effects.

About FACT-physical, the mean score decreased. Narrating patients' stories may contribute to expressing their thinking or emotion freely, resulting in alleviation of their burden of symptoms. In home hospice, there are few who visit patients at home, patients sometimes require someone to talk to freely. The previous study shows a longer survival for the intervention group than the control group [13]. The effects of the narrative approach on physical aspects needs to be examined in the future.

About the Life Satisfaction score, although there was no change, the score 22 of points in this study was higher than the standard 21 points of generally healthy people. Some of the participants said that "I can live in my house with my family, and I am satisfied with my life." Since patients could choose home hospice with their own intention, they are satisfied with their lives and the Life Satisfaction score is as much as with healthy people. The place where time is spent at the end of life is a very important factor for a good death [23], the narrative approach at home hospice may promote their QOL.

The Hope score increased a little. Some of the patients found hope through their narrative. It is important for medical staff to hear a patients' hope directly. If the staff understands a patients' hopes, they may be able to help to realize those hopes. These days, Advanced Care Planning (ACP) seems to be important for a patients' QOL [24].

In future, we need to increase the number of participants and confirm these results.

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