

Burden on Oncologists When Communicating the Discontinuation of Anticancer Treatment

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Objective: Communicating the discontinuation of anticancer treatment to patients is a difficult task. The primary aim of this study was to clarify the level of oncologist-reported burden when communicating about discontinuation of an anticancer treatment. The secondary aims were (i) to identify the sources of burden contributing to their levels and (ii) to explore the useful strategies to alleviate their burden.

Methods: A multicenter nationwide questionnaire survey was conducted on 620 oncologists across Japan (response rate, 67%).

Results: High levels of perceived burden were reported by 47% of respondents, and 17% reported that they sometimes, often or always wanted to stop oncology work because of this burden. There was a significant association between high levels of burden and: a feeling that breaking bad news would deprive the patient of hope; concern that the patient's family would blame the oncologist; concern that the patient may lose self-control; and a feeling that there was not enough time to break the bad news. Strategies perceived to be useful by oncologists included training in how to effectively communicate to patients discontinuation of anticancer treatment, a reduction in total workload to allow sufficient time to break bad news, and development of a multidisciplinary model to facilitate cooperation with other professionals and facilities.

Conclusions: Many oncologists reported high levels of burden relating to communication of discontinuation of anticancer treatment. A specific communication skills training program, sufficient time for communication and development of a multidisciplinary model could help alleviate the burden on oncologists.

Key words: burden – oncologists – communicating

INTRODUCTION

Breaking bad news is a stressful experience for the oncologist (1–6); moreover, it contributes to diminished confidence in communication skills and higher expectations of a negative outcome. The experience of dealing with distressed, angry and reproachful patients is also associated with

burnout (7). Previous studies have suggested that oncologist-perceived burden is caused by several factors associated with the patient, the patient's family, the oncologists themselves and the medical environment (8,9). An oncologist's communication style affects the extent of emotional distress felt by the patient and the patient's family (10). The most

difficult conversations involved discussing the discontinuation of curative treatment and admission to a hospice (4); therefore, it is important to clarify the extent of the burden experienced by the oncologist when communicating the discontinuation of anticancer treatment.

Many studies have been conducted to clarify patients' preferences and experiences in receiving bad news in oncology settings (11–14), and several clinical guidelines and expert recommendations have been published (1,15,16). Moreover, recent intervention trials have demonstrated that structured communication skills training can improve physicians' skills in breaking bad news (17–19).

Despite the existence of many experience-based recommendations and studies into the psychological effects on patients and their families, to our knowledge, only a few studies have explored the extent of the burden on oncologists when communicating the discontinuation of anticancer treatment. Therefore, the aims of the present study were to: (i) clarify the level of oncologist-perceived burden when communicating the discontinuation of anticancer treatment to patients; (ii) identify factors contributing to this burden; and (iii) explore potentially useful strategies to alleviate oncologist-perceived burden.

PATIENTS AND METHODS

SUBJECTS

The present study was a cross-sectional anonymous multicenter nationwide survey of oncologists in cancer centers across Japan. Questionnaires were mailed to 620 eligible oncologists in February 2007 and again 2 months later to those oncologists who had not yet responded. If the oncologists did not want to participate in the survey, we requested that they return the questionnaire without replying to any of the questions. The participating institutions were 12 cancer centers selected from the 15 cancer centers that make up the Japanese Association of Clinical Cancer Centers.

We recognized potential sampling bias with this method, but decided to use convenient institutions because we felt that the risk of sampling bias would be minimized by a large number of participants.

Eligibility criteria for the participants were as follows: (i) oncologists specializing in gastroenterology, respiratory medicine, breast oncology, hematology, medical oncology, urology, gynecology, otolaryngology, orthopedics, pediatrics, neurosurgery or dermatology; and (ii) the oncologist's name had to appear on his/her medical facility's website. The website of all Japanese cancer centers shows the complete list of all physicians in that center. We regarded the completion and return of the questionnaire as consent to participate in the study. The institutional review board of the principal investigator confirmed the study's ethical and scientific validity.

QUESTIONNAIRE

A questionnaire was developed based on a review of the literature (2,3,8,9) and discussions among the authors. Content validity was assessed by full agreement of the authors, and face validity was confirmed by a pilot test of 20 potential participants.

As background data, oncologists reported their age, gender, clinical experience in oncology, specialty, previous experience with formal communication skills training, attitudes toward disease and prognosis disclosure for terminally ill patients, and the number of patients to whom they would usually communicate the discontinuation of anticancer treatment annually.

The primary endpoint was oncologist-perceived burden imposed by communicating the discontinuation of anticancer treatment to patients. Given the lack of existing validated instruments, the following outcome parameters were developed by the authors. First, the level of oncologist-perceived burden was evaluated by the question, 'What level of burden do you feel when you communicate with patients about discontinuation of anticancer treatment?' Answers to this question were rated on a five-point scale ranging from 1 (I do not feel any burden at all) to 5 (I feel a heavy burden). In addition, we investigated the impact of the burden on motivation to continue working in oncology by asking oncologists, 'How often do you feel some level of desire to stop oncology work due to this burden'. Again, answers were rated on a five-point scale ranging from 1 (not at all) to 5 (always).

We extracted 20 potential sources of burden from the literature (8,9) and questioned oncologists on their level of perceived burden relating to each of these sources. Oncologists were requested to rate their degree of burden on a five-point Likert-type scale ranging from 1 (I do not feel any burden) to 5 (I feel a heavy burden).

In addition, we developed a list of 14 potentially useful strategies to alleviate oncologists' perceived burden derived from a previous report (20) and from a qualitative study using in-depth interviews with three oncologists. The oncologists were requested to rate their level of agreement with each of these strategies on a six-point Likert-type scale ranging from 1 (not necessary) to 6 (absolutely necessary).

STATISTICAL ANALYSES

For comparisons, respondents were classified into two groups: oncologists who rated themselves as 'heavily burdened' or 'burdened' (high-level burden) and then all other oncologists (low-level burden). This cut-off point was selected on the basis of the actual distribution of the data and enabled the entire sample to be divided into two equal-sized groups for comparison.

To explore the determinants of levels of oncologist-reported burden, we screened 7 background variables and 20 sources of burden. Univariate analyses were performed using Student's *t*-test or the χ^2 test, as appropriate. To assess the

results in 20 comparisons, the *P* value necessary for statistical significance was defined as 0.0025 (0.05/20) using the Bonferroni correction. Multiple logistic regression analyses were then performed using a forward elimination procedure. All potential predictors with statistical significance as ascertained by the univariate analyses were included as independent variables in multiple logistic regression analyses. All analyses were performed using SPSS version 11.0.

RESULTS

Of the 620 questionnaires mailed to oncologists, 10 were undeliverable because of incorrect addresses and 416 oncologists returned questionnaires, resulting in a response rate of 67%. Of the questionnaires returned, 3 were excluded due to missing data in primary endpoints and 19 were returned without any of the questions being answered. Thus, a total of 394 responses were analyzed, giving an effective response rate of 67% (394/591). The oncologists' characteristics are summarized in Table 1.

Overall levels of oncologist-reported burden relating to communication of the discontinuation of anticancer treatment were: heavily burdened, 13%; burdened, 34%; slightly burdened, 37%; not particularly burdened, 13%; or not burdened at all, 1.3% (Table 2). Clinical oncologists rated their level of desire to stop oncology work because of this burden as: not at all, 55% (*n* = 218); rarely, 26% (*n* = 106); sometimes, 11% (*n* = 45); often, 5.3% (*n* = 21); or always, 1.0% (*n* = 4).

The oncologists' ratings of the 20 potential sources of burden relating to the communication of discontinuation of anticancer treatment are given in Table 3. More than 20% of respondents reported feeling 'heavily burdened' or 'burdened' by the following factors: insufficient time to break bad news; feeling that breaking bad news will deprive the patient of hope; the possibility that the breaking of bad news is interrupted by other tasks; concern that the patient may lose self-control; opposition from the patient's family to breaking bad news to the patient; the fact that evidence from a certain group is not applicable to every patient; and, finally, an inability to answer philosophical questions regarding death and the value of life.

Univariate analysis (Table 4) showed that oncologists with high-level burden were significantly more likely to report the following concerns: feeling that breaking bad news will deprive the patient of hope; concern that the oncologist may be blamed by the patient's family; concern that the patient may lose self-control; insufficient time to break bad news; possibility that the time for breaking bad news is interrupted by other tasks; opposition from the patient's family to breaking bad news to the patient; evidence from a certain group is not applicable to every patient; an inability to answer philosophical questions regarding death and the value of life; feeling a sense of guilt because oncologists cannot provide adequate treatment; concern that the oncologist may be

Table 1. Background of respondent oncologists

Age (years)	
Median	43
Inter-quartile range	37–50
Male gender [no. (%)]	371 (91)
Oncology experience (years)	
Median	15
Inter-quartile range	8–20
Number of communications concerning discontinuation of anticancer treatment annually	
Median	8
Inter-quartile range	3–15
Attitudes toward disease and prognosis disclosure for terminally ill patients ^a [no. (%)]	
Routinely, without patient's request	55 (14)
If necessary, without patient's request	234 (59)
If necessary, and if the patient explicitly asks	78 (19)
Routinely, and if the patient explicitly asks	21 (5.3)
Specialty ^a [no. (%)]	
Gastroenterology	116 (30)
Respiratory medicine	50 (13)
Breast oncology	42 (10)
Hematology, medical oncology	42 (10)
Urology	32 (8.3)
Gynecology	30 (7.8)
Otolaryngology	24 (6.2)
Orthopedics	19 (4.9)
Neurosurgery	12 (3.1)
Pediatrics	13 (3.3)
Dermatology	5 (1.3)
Received formal training in breaking bad news [no. (%)]	59 (16.5)

^aPercentages do not add up to 100% because of missing data.

criticized by the patient; scientific evidence is not always predictable or reproducible; opposition from patients to breaking bad news to their families; fear of talking to patients whom the oncologist do not know very well; lack of confidence in oncological medical skills; uneasiness in changing roles from curing patients to caring for patients; and a concern that an objective stance cannot be maintained if the oncologist becomes too intimate with the patient.

Multiple logistic regression analysis (Table 4) revealed that independent determinants of high-level burden were: feeling that breaking bad news will deprive the patient of hope; concern that the oncologist may be blamed by the patient's family; concern that the patient may lose self-control; and insufficient time to break bad news. Seven backgrounds of the oncologist, including age, specialty, attitudes toward disease and prognosis disclosure for terminally ill patients, oncology experience, previous experience with

formal communication skills training, or number of communications concerning discontinuation of anticancer treatment annually, are not the determinants of levels of oncologist-reported burden.

Strategies to relieve oncologist-reported burden when communicating the discontinuation of anticancer treatment were also investigated. Table 5 lists the percentage of

Table 2. Levels of oncologist-reported burden when communicating discontinuation of anticancer treatment

	No. (%)
Heavily burdened	53 (13)
Burdened	136 (34)
Slightly burdened	147 (37)
Not particularly burdened	53 (13)
Not burdened at all	5 (1.3)

Table 3. Sources of oncologist-reported burden when communicating discontinuation of anticancer treatment

	'Not burdened at all', no. (%)	'Not particularly burdened', no. (%)	'Slightly burdened', no. (%)	'Burdened', no. (%)	'Heavily burdened', no. (%)
Insufficient time to break bad news	12 (3.1)	61 (15)	90 (22)	151 (36)	82 (20)
Feeling that breaking bad news will deprive the patient of hope	12 (3.1)	34 (8.7)	152 (37)	135 (33)	63 (15)
Possibility that the time for breaking bad news is interrupted by other tasks	18 (4.6)	86 (21)	102 (25)	120 (29)	71 (17)
Concern that the patient may lose self-control	16 (4.1)	83 (21)	163 (39)	108 (26)	25 (6.0)
Opposition from family members to breaking bad news to the patient	39 (9.9)	96 (24)	134 (32)	91 (22)	36 (8.7)
Evidence from a certain group does not always apply to the patient	43 (10)	122 (31)	133 (32)	70 (17)	28 (6.7)
The oncologist is unable to answer philosophical questions regarding death and the value of life	37 (9.5)	122 (31)	140 (34)	74 (18)	21 (5.0)
Concern that the oncologist may be blamed by the patient's family	73 (18)	141 (35)	104 (25)	63 (15)	15 (3.6)
Feeling a sense of guilt because oncologists cannot provide effective anticancer treatment	83 (21)	140 (35)	102 (25)	56 (14)	14 (3.4)
Opposition from patients to breaking bad news to their families	70 (17)	171 (43)	87 (21)	47 (11)	19 (4.6)
Concern that the oncologist may be criticized by the patient	75 (19)	149 (37)	107 (26)	56 (14)	9 (2.2)
Fear of talking to patients whom oncologist does not know very well	84 (21)	138 (35)	108 (26)	54 (13)	10 (2.4)
Scientific evidence is not always predictable or reproducible	43 (10)	122 (31)	133 (32)	70 (17)	28 (6.7)
Lack of confidence in oncological medical skills	63 (16)	172 (43)	106 (26)	49 (12)	5 (1.2)
Concern that the oncologist does not have the latest knowledge	80 (20)	179 (45)	97 (23)	36 (8.7)	2 (0.5)
Uneasiness in changing roles from curing patients to caring for patients	111 (28)	176 (44)	68 (16)	34 (8.2)	4 (1.0)
Concern that oncologists cannot answer all knowledge-based questions posed by the patient	94 (24)	186 (47)	81 (20)	29 (7.0)	3 (0.7)
Oncologists fear their own illness and death	122 (31)	178 (45)	62 (15)	26 (6.3)	4 (1.0)
Concern that an objective stance cannot be maintained if the oncologist becomes too intimate with the patient	89 (22)	195 (49)	85 (20)	24 (5.8)	3 (0.7)
Fear that oncologists themselves may become very emotionally involved, such as expressing anger or sadness	107 (27)	209 (53)	59 (14)	18 (4.3)	0 (0)

Percentages do not add up to 100% due to missing data.

oncologists who agreed with each of the 14 strategies suggested to alleviate oncologists' perceived burden. More than 20% of respondents considered the following strategies to alleviate oncologist-reported burden as 'absolutely necessary': that an inpatient hospice is readily available and that patient information is exchanged smoothly among facilities; quiet and private rooms are available for breaking bad news; after breaking bad news, a nurse, psychologist or medical social worker is available to provide emotional support; and a reduction in oncologists' total workload to give them sufficient time to break bad news.

DISCUSSION

To the best of our knowledge, this is the first large multicenter nationwide survey to investigate oncologist-reported burden when communicating the discontinuation of anticancer treatment. The first important finding of the present study was the demonstration of the oncologist-reported burden when

Table 4. Determinants of oncologist-reported burden when communicating discontinuation of anticancer treatment

	Univariate analyses			Multivariate analyses	
	Low level (n = 206)	High level (n = 190)	P value	Odds ratio (95% CI)	P value
Feeling that breaking bad news will deprive the patient of hope	3.1 ± 0.9	3.8 ± 0.8	<0.01	1.8 (1.4–2.5)	<0.01
Concern that the oncologist may be blamed by the patient's family	2.1 ± 0.8	2.8 ± 1.1	<0.01	1.5 (1.2–1.9)	<0.01
Concern that the patient may lose self-control	2.8 ± 0.8	3.4 ± 0.9	<0.01	1.4 (1.1–1.9)	<0.01
Insufficient time to break bad news	3.3 ± 1.0	3.8 ± 0.9	<0.01	1.2 (0.99–1.6)	0.049
Possibility that the time for breaking bad news is interrupted by other tasks	3.1 ± 1.0	3.5 ± 1.1	<0.01		
Opposition from family members to breaking bad news to the patient	2.7 ± 1.0	3.2 ± 1.1	<0.01		
Evidence from a certain group does not always apply to every patient	2.6 ± 0.9	3.0 ± 1.1	<0.01		
The oncologist is unable to answer philosophical questions regarding death and the value of life	2.5 ± 0.8	3.0 ± 1.0	<0.01		
Feeling a sense of guilt because oncologists cannot provide effective anticancer treatment	2.1 ± 0.9	2.7 ± 1.1	<0.01		
Concern that the oncologist may be criticized by the patient	2.1 ± 0.8	2.7 ± 1.0	<0.01		
Scientific evidence is not always predictable or reproducible	2.3 ± 0.8	2.7 ± 1.0	<0.01		
Opposition from patients to breaking bad news to their families	2.2 ± 0.8	2.6 ± 1.2	<0.01		
Fear of talking to patients whom the oncologist does not know very well	2.2 ± 0.9	2.5 ± 1.1	<0.01		
Lack of confidence in oncological skills	2.2 ± 0.8	2.5 ± 0.9	<0.01		
Uncasiness in changing roles from curing patients to caring for patients	1.9 ± 0.8	2.3 ± 0.9	<0.01		
Concern that an objective stance cannot be maintained if the oncologist becomes too intimate with the patient	1.9 ± 0.7	2.2 ± 0.8	<0.01		
Concern that the oncologist does not have the latest knowledge	2.1 ± 0.8	2.2 ± 0.9	0.24		
Fear that the oncologist may become very emotionally involved, such as expressing anger or sadness	1.9 ± 0.6	2.0 ± 0.8	0.24		
Concern that the oncologist cannot answer all knowledge-based questions posed by the patient	2.0 ± 0.8	2.2 ± 0.9	0.34		
Fear of the oncologists' own illness and death	1.9 ± 0.7	2.0 ± 1.0	0.78		

Oncologists who rated their burden level as heavily burdened or burdened (high-level group) are compared as a single group against all others (low-level group). Multiple logistic regression analyses used the high-level burden group as the dependent variable. Each condition was rated on a scale of 1 (do not feel any burdened) to 5 (feel heavily burdened).

communicating the discontinuation of anticancer treatment to patients. Of the oncologists surveyed, 47% reported high levels of burden when communicating the discontinuation of anticancer treatment. Moreover, 17% of the oncologists surveyed reported that they sometimes, often or always want to stop oncology work because of this burden. Multiple studies have revealed that a major contributor to physicians' burnout is communication with patients and families (21–26). The present study confirms that communication with patients and families is a major source of oncologists' work-related stress. In particular, the present study highlights that communicating the discontinuation of anticancer treatment can be a heavy burden for oncologists and that it is urgent that strategies are developed to alleviate this burden.

The present study also evaluated oncologists' opinions regarding the strategies likely to be effective in reducing this burden. The strategies perceived to be potentially effective

included: ready availability of an inpatient hospice and smooth exchange of patient information among facilities; availability of quiet and private rooms for the breaking of bad news; the provision of emotional support from a nurse, psychologist or medical social worker after the patient has received the bad news; and a reduction in oncologists' total workload to give them sufficient time to break the bad news.

Moreover, multiple logistic regression analyses revealed that independent determinants of high-level burden were: a feeling that breaking bad news will deprive the patient of hope; concern that the oncologist may be blamed by the patient's family; concern that the patient may lose self-control; and insufficient time to break bad news.

These results reveal that there are three main areas that, if addressed, could significantly alleviate oncologist-reported burden: (i) improving oncologists' communication skills; (ii) allowing sufficient time for communication with patients and

Table 5. Oncologists' opinion on strategies suggested to alleviate the burden associated with communicating discontinuation of anticancer treatment

	Necessary (%)	Absolutely necessary (%)
Inpatient hospice is readily available and patient information is exchanged smoothly among facilities	49	36
Quiet and private rooms are available for breaking bad news	56	25
After breaking bad news, a nurse, psychologist or medical social worker is available for emotional support	63	24
A reduction in the oncologist's total workload to give sufficient time for the breaking of bad news	54	23
While breaking bad news, a nurse, psychologist or medical social worker is available for emotional support	56	13
Having an opportunity to attend educational workshops about how to break bad news	51	6.8
A psychiatrist or psychologist is available for consultation if the oncologist feels overburdened	42	6.6
Before breaking bad news, having the opportunity to discuss the situation with colleagues and receive advice	54	6.1
After breaking bad news, specialists in physician-patient communication are available to give advice to the oncologist about how they should break bad news	60	5.5
Having opportunities to share experiences and feelings with the colleagues within the hospital	51	5.5
Before breaking bad news, information about what the patient and family want to know is available from nurses	65	5.0
Before breaking bad news, the oncologist receives a memo from the patient and family about what they want to know	61	3.8
After breaking bad news, the oncologist receives a questionnaire to identify what the patient and the family are feeling and thinking	65	3.3
Have an opportunity to share experiences and feelings with colleagues from other hospitals	47	3.0

their families; and (iii) developing a multidisciplinary care model with other professionals and facilities.

This study emphasizes the importance of communication skills. Previous studies suggested that communication skills training increases both patient satisfaction (27,28) and oncologists' confidence (29). However, to the best of our knowledge, existing communication skills training does not specifically address issues surrounding the discontinuation of anticancer treatments. The present study highlights the importance, under these difficult circumstances, of helping the patient maintain hope, dealing with the oncologists' fear of being blamed by the patients and their families, and strengthening patient self-control. The results indicate that a communication skills training program specifically targeting skills for communicating the discontinuation of anticancer treatment needs to be developed. This program should include strategies to deal with oncologists' concerns, such as that by breaking bad news to a patient, the oncologist will deprive the patient of hope, that the oncologist may be blamed by the patient's family and that the patient may lose self-control.

The oncologists surveyed stressed the importance of a reduction in their total workload to give them sufficient time to facilitate effective communication with patients. A previous study suggested that physicians face excessive workloads that are associated with a lower quality of patient care (30). Several studies have suggested that the perception of having insufficient time to communicate with patients is the factor most strongly associated with oncologist burnout (22,31). In Japan, according to a 2008 revision by the Ministry of Health, Labor and Welfare in Japan of the payment of fees for medical treatment, an additional fee for

outpatient care can be applied when a physician is directly involved in clinical practice for 5 min or longer. This indicates that the Ministry of Health, Labor and Welfare in Japan defines the time for consultation and implies that most physicians in Japan are too busy to spend 5 min or more on each outpatient. These results stress that a reduction in physicians' workload is vital.

Many oncologists surveyed in the present study agreed with the importance of multidisciplinary cooperation with other professionals and facilities. Two types of cooperation were considered to be particularly valuable: (i) that after breaking bad news, a nurse, psychologist or medical social worker was available to follow up with patients and their families; and (ii) the availability of other facilities, especially inpatient palliative care units. Previous studies have shown that cancer patients' participation in nurse-led interventions resulted in an improvement in depressive moods (32,33). Multiple intervention studies have indicated that practice-based interprofessional collaboration can improve patients' health-care processes and outcomes (34). Furthermore, existing literature indicates that regional palliative care programs succeed in increasing family satisfaction (35,36). These findings suggest that developing a multidisciplinary team to support oncologists, not only within a hospital, but also beyond the hospital (as a region), is of considerable importance in achieving patient and family satisfaction. As the number of palliative care units in Japan is not enough, increasing the reimbursement for inpatient hospice would be important as policy. Moreover, because oncologist burden was not measured in these previous studies, prospective observational or interventional studies are needed to determine whether a team

approach, such as in-hospital and regional palliative care programs, could alleviate oncologist burden.

The limitations of the present study include the moderate (67%) effective response rate, which may mean that the entire oncological population is not represented by the oncologists who participated in the present study. Furthermore, because this study was performed in Japan, the results are likely to be influenced by factors relating to Japanese culture and the Japanese health-care system and, as such, may not be applicable to other countries.

In conclusion, a considerable number of oncologists experienced high levels of burden in communicating the decision to discontinue anticancer treatment. To alleviate oncologist burden, potentially useful strategies include: (i) communication skills training specifically targeting discontinuation of anticancer treatment; (ii) a reduction in total workload to allow oncologists sufficient time to break bad news; and (iii) the development of a multidisciplinary model to facilitate cooperation with other professionals and facilities.

Authors' Contribution

H.O.: conception and design, provision of the study material, collection of data, data analysis and interpretation, manuscript writing and administrative support. T.M.: conception and design, provision of the study material, data analysis and interpretation, final approval of the manuscript, administrative support, and financial support. T.E., H.A., K.T., A.O. and K.S.: provision of the study material and final approval of the manuscript.

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Conflict of interest statement

None declared.

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Factors that influence the efficacy of bereavement life review therapy for spiritual well-being: a qualitative analysis

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Abstract

Purpose We have previously shown that bereavement life review therapy improves the spiritual well-being of a bereaved family, but the factors that influence the efficacy of this therapy have not been determined. Therefore, this study was performed to identify factors associated with improvement of spiritual well-being of bereaved families.

Methods The participants were 21 bereaved family members who lost a relative who had been treated in a palliative care unit in Japan. The family members received the

Bereavement Life Review over two sessions of about 60 min each. In the first session, the bereaved family member reviewed their memories of the deceased relative with a clinical psychologist and answered several questions. After the first session, the psychologist made an album. In the second session, the family member and the psychologist confirmed the accuracy of the contents of the album. Assessment was performed using the Functional Assessment Chronic Illness Therapy-Spiritual score, based on which the participants were separated into effective and non-effective groups. Factors were extracted from the narrative of the therapy using a text-mining software.

Results Factors such as “good memories of family,” “loss and reconstruction,” and “pleasant memories of last days” were commonly found in the effective group, whereas factors such as “suffering with memories,” “regret and sense of guilt,” and “disagreement on funeral arrangements” were more common in the non-effective group.

Conclusions Factors like “good memories of families,” “loss and reconstruction,” and “pleasant memories of last days” were associated with the improvement of spiritual well-being of bereaved families.

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Keywords Cancer patients · Bereavement life review ·
Spiritual well-being · Effective factors

Introduction

Bereaved family members may experience physical or psychological problems as a grief reaction [1, 2]. An unresolved or complicated reaction may require emotional and behavioral therapy for spiritual dysfunction [3]; disbelief about death; lack of acceptance of death; prolonged searching and yearning [4]; hopelessness [5]; and

the link between suicide [6], hopelessness [7], and depression [8]. To cope with these reactions, hospices provide support such as counseling or befriending [9], a meaning-oriented approach for grief [10], and cognitive behavior therapy for complicated grief [11]. In Japan, memorial cards and services are frequently provided, included by many health care professionals [12] and support groups [13]. Staff members in palliative care units (PCUs) recognize the need for individualized care [12], but there are few studies on the effect of the intervention on the spiritual well-being of bereaved family members.

The following are theories of grief process, the Four Task theory by Warden [13] such as accepting the loss, acknowledging the pain and working through it, taking on new role, and finding an appropriate place, the Dual Process by Strobe and Schut [14] in which the bereaved families experience both loss-oriented or restoration orientated coping, or the Reconstruction of Meaning Making therapy based on constructivism by Neimeyer, Burke, Mackay [15] in which the bereaved families make new meaning by re-telling story. These theories include telling or reviewing stories of the bereaved families. Thus, we developed the Bereavement Life Review as psychotherapy by reviewing lives especially for improving the spiritual well-being of bereaved families since they often lose meaning or purpose to live because of loss of the important person, and it relates with quality of life [16]. Spiritual well-being is defined as having a meaning for life or purpose, peace of mind, and relationships with others [17, 18].

The Bereavement Life Review includes a review of memories with the deceased person in the first session. The interviewer makes an album after the first session and then confirms the contents of the album with the participant in the second session. We have shown that this therapy increases the spiritual well-being of a bereaved family [19]; however, the factors that influence the efficacy of the therapy are unclear. Therefore, the present study was performed to identify factors that make the Bereavement Life Review effective for the improvement of spiritual well-being.

Methods

Participants

Primary physicians identified potential participants based on the following inclusion criteria: (1) the family member was bereaved due to the death of a relative from cancer in a PCU, (2) the family member was ≥ 20 years old, and (3) the family member was capable of replying to the questionnaires. The exclusion criteria were that the participant (1)

may suffer serious psychological distress as determined by the primary physician and (2) was not aware of the diagnosis of malignancy.

The study was performed as part of a large cross-sectional anonymous nationwide survey of bereaved families of cancer patients who had been admitted to 100 PCUs in Japan. The PCU is the most common type of specialized palliative care service in Japan. Therefore, we chose bereaved family members of patients in PCUs as the subjects of the study. All PCUs provide palliative care through a multidisciplinary team, including attending physicians, nurses, psychiatrists, clinical psychologists, and medical social workers. Some PCUs also provide regular religious care by pastoral care workers or priests. The details of the service contents have been given elsewhere [20]. Questionnaires about the palliative care service were mailed to bereaved families in June 2007 and again in August 2007 to non-responding families. The detailed methods of the larger study have been given elsewhere [21, 22].

In the questionnaire, the families indicated if they were willing to participate in another research interview. One of the co-authors made a list of registered participants who were willing to undergo an interview and mailed this list to the interviewer. The interviewer selected 64 registered participants for interview based on a consideration of traveling distance and mailed an explanation of the Bereavement Life Review to these participants. Subsequently, 28 family members replied with consent to contact them for an interview. The interviewer first contacted the family member by phone, and seven were eliminated from the study due to difficulties with movement ($n=1$), illness ($n=1$), very long traveling distance ($n=1$), withdrawal of consent ($n=2$), and inability to contact ($n=2$). Thus, 21 family members participated in the study (six males, mean age 65 ± 15.1 years old; 15 females, mean age 60 ± 11.7 years old).

Questionnaires

The Japanese version of the Functional Assessment Chronic Illness Therapy-Spiritual (FACIT-Sp) scale [23], which was translated from the original version of Peterman et al. [18], was used to measure spirituality. Items on the FACIT-Sp are scored on 5-point scales ranging from 4 (strongly agree) to 0 (strongly disagree).

Procedures

The ethical and scientific validity of the study was approved by the institutional review board of St. Mary's College. Interviews were conducted individually by a clinical psychologist in a college office. Two interview sessions were conducted in the Bereavement Life Review. Participants

orally completed a questionnaire about spiritual well-being (FACIT-Sp) before the first session and after the second session. Each interview session lasted about 30 to 60 min.

In the first session, participants reviewed their life and their memories of the deceased along the following questions: (1) What is the most important thing in your life and why? (2) What are your strongest memories of the patient? (3) In taking care of the patient, what is your most pleasant memory with the patient? (4) What growth did you experience through taking care of the patient? (5) What is the most important role you have played in your life? (6) What are you proudest of in your life? The narratives of the interviews of the subjects were recorded. After the first session, in order to make an album for the participants, the interview was transcribed verbatim and the therapist made a simple album. In the album, key words or impressive words from the answer to each question were selected by the psychologist, and she pasted photos or drawings from books or magazines that were related to the participants' words or phrases in order to make the album beautiful and memory-provoking. In the second session, the participants and the psychologist viewed the album together and agreed upon the contents.

Data analysis

Transcribed verbatim in the interview which was used to make an album was also used for data analysis. To identify factors associated with spiritual well-being, we used the text-mining program Word Miner [24, 25] to find specific words within the transcribed verbatim. Since we wanted to know the contents for subjects with strong improvement of spiritual well-being, we examined the relationships between the FACIT-Sp score and the contents extracted by the software. Patient narratives were first divided into meaningful words or

phrases, and words with the same meaning were substituted, for example, both "mom" and "mother" were included as "mother." Articles or punctuation marks were deleted, leaving only meaningful words, which are referred to as "fragments." A correspondence analysis was performed between the fragments and FACIT-Sp scores, and a significance test was conducted after this analysis to find fragments with a significant relationship with the FACIT-Sp scores.

A total of 333 fragments were chosen from the narratives of the 21 bereaved family members. Differences in FACIT-Sp scores before and after the interviews were calculated and the change in score was found to range from -12 to 14. Based on the median change of 3.0, the 21 patients were divided into an effective group (scores from 3 to 14) and a non-effective group (scores from -12 to <3).

Results

Factors in the Bereavement Life Review with an association with improvement of spiritual well-being were identified by correspondence analysis. This accounted for 80% of the variance, indicating the validity of the analysis. The fragments found in the correspondence analysis and the results of the significance test are shown in Tables 1 and 2 for the effective and non-effective groups, respectively. A high score in these tables indicates a fragment in the narrative that contributed to the efficacy of the therapy. The most important fragments were tabulated after performance of the significance test. We referred to three factors in each group.

In the effective group (Table 1), fragments such as "Mother," "Father" or "Going on an overseas trip" ranked high and we classified these as "good memories of family."

Table 1 Fragments chosen by bereaved family members in the effective group

Rank	>12 to ≤14	Scores	>8 to ≤10	Scores	>5 to ≤8	Scores	≥3 to ≤5	Scores
1	Mother	7.07	Husband	5.35	Rehabilitation	3.08	Wife	9.50
2	My parents' home	4.34	Carefree life	3.81	Last	2.96	Elders' club	3.61
3	Not being settled	3.52	Sense of loss	3.81	I was permitted to do everything.	2.78	Many things happened.	2.76
4	Father	3.35	My brain began to become active.	3.81	My father moved into a private room.	2.78	Lucky	2.76
5	Pet	3.04	I was surprised.	2.93	Everyone	2.44	Various matters	2.24
6	My father could not eat.	3.04	Remembering	2.46	1-year memory	2.44	My wife had good taste.	2.24
7	Going on an overseas trip	2.49	I had lost interest.	2.39	Last birthday party	2.44	Department	2.24
8	Maruyama vaccination	2.49	Regret for not leaving	2.39	Sedation	2.44	Process	2.24
9	My father had pain.	2.49	I did not think of suicide.	2.39	Red cross hospital	2.44	Recurrence	2.24
10	Pass	2.49	I confronted problems.	2.39	My mother was confined for 16 years.	2.06	I lost my job.	2.24

Table 2 Fragments chosen by bereaved family members in the non-effective group

Rank	≥ -12 to <-1	Scores	≥ -1 to <1	Scores	≥1 to <2	Scores	≥2 to <3	Scores
1	Keeping my home is my role.	3.72	Scattering ashes	4.80	Mother	4.46	I should have talked with my mother.	2.81
2	I have positive thinking.	2.99	Have gone on a trip	2.73	Seeming to live longer	3.49	Living for all my worth	2.81
3	My father was strict.	2.55	Husband requested scattering ashes funeral style	2.33	Sense of guilt	2.53	My children were college students.	2.81
4	I have lost interest.	2.06	Fukuoka	2.33	Nursing care	2.25	My encounter is important	2.81
5	Struggling with husband's memories	2.06	Certification of a helper	1.85	Regret	2.14	Changing clothes	2.81
6	I was possessed by my husband's soul.	2.06	Kumamoto	1.85	Not being able to give hopeful care	2.14	My mother had problems.	2.81
7	Now	2.03	Dazaifu (funeral place)	1.85	Mission and duty of taking care	1.69	My mother worked.	2.81
8	Not proud	1.53	Having seen a patient	1.85	I was told to cut the grass.	1.69	My mother died.	2.01
9	I went on errands.	1.45	Hospice	1.80	Thanks for mother	1.69	The hospice ward was good	1.26
10	Birthday party with a great grandchild	1.45	Husband	1.78	I was born with my mother.	1.69	Children	1.06

Fragments such as “husband,” “sense of loss,” and “my brain began to become active” also ranked highly and were classified as “loss and reconstruction.” Fragments such as “rehabilitation,” “last,” and “last birthday party” were also common and were classified as “pleasant memories of last days.”

In the non-effective group (Table 2), fragments such as “keeping my home is my role,” “struggling with husband memories,” and “I was possessed by my husband’s soul” ranked high and were classified as “suffering with memories.” Fragments such as “scattering ashes” and “husband requested scattering ashes funeral style” also ranked high and were classified as “disagreement on funeral arrangements.” Fragments such as “sense of guilt,” “nursing care,” and “regret” were also common and were classified as “regret and sense of guilt.”

Discussion

In the effective group, “good memories of family,” “loss and reconstruction,” and “pleasant memories of last days” were identified as common factors. “Good memories of family” indicates that good memories promoted the life review and improved the spiritual well-being of the bereaved families. Those family members with good family memories had good human relationships, and the importance of good human relationships for Japanese subjects is in accord with the findings of previous studies [21, 26]. “Loss and reconstruction” indicates that families who had grieved sufficiently might then be able to

reconstruct their life. This supports the finding that spiritual growth during bereavement occurs only when a person spends time in both the loss-oriented and restoration-oriented areas [27, 28]. “Pleasant memories of last days” indicates that bereaved family members who had enjoyed a good time, such as talking or eating, with the patient in the PCU retained precious memories that improved spiritual well-being.

Considering these factors, we present a new model, the Memory Reinforce theory

In this model, the Bereavement Life review reinforces good past memories of the bereaved families who had good memoirs toward acceptance of loss. It also promotes the bereaved who had bad or bitter memories associated with a patient’s death to grieve fully, and it changes bad or bitter memories to good memories. Also, it reinforces the nearest pleasant memories of last days toward beautiful memories (Fig. 1).

In the non-effective group, “struggling with memories,” “disagreement on funeral arrangements,” and “regret and

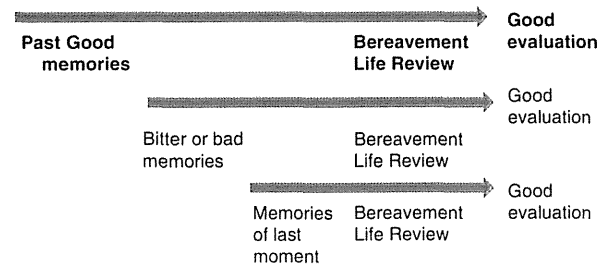


Fig. 1 Memories reinforcement model from the effective group

sense of guilt” were identified as common factors. “Suffering with memories” indicates that the families were grieving or mourning for the deceased. One woman said that “my husband’s soul comes to me” and she could not enjoy her memories of her husband. “Disagreement on funeral arrangements” indicates problems among family members associated with the funeral, which may have caused bad relationships. One man desired “scattering ashes” and his family had agreed, but other relatives disagreed. A grave after a funeral is a place of peace for many Japanese people and disagreement on this issue is an important factor [29]. “Regret and sense of guilt” suggests that some of the bereaved family members felt regret and guilt because they thought they had not visited the patient sufficiently or that their choice of medical treatment or place of recuperation was inappropriate. This supports the idea that people who cannot accept the past and resolve their regret are often self-critical and incapable of accepting their imperfections and limitations [30].

It is a wonder that the Bereavement Life Review is not so effective for the bereaved families in the non-effective group because they might be in the middle of the grief process and their spiritual well-being did not improve through this therapy in the present study. Thus, we need to examine their state of mind for a longer time with more interview sessions, and if this therapy is not effective even though there are many sessions, other kinds of interventions like mindfulness [31, 32], cognitive behavior therapy [33], or support group might be effective.

The limitations of the study include a relatively small number of participants and that almost all the participants had good relationships with the deceased; however, the relationships among the bereaved family members may not have always been good. These factors make it difficult to generalize the findings and further studies are needed to confirm the present results. Within these limitations, we conclude that the Bereavement Life Review is likely to be effective for bereaved families who have good memories of a deceased relative with whom they had a relatively pleasant time in the last days and who have undergone sufficient grieving and tried to reconstruct their lives.

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Conflict of interest None

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おかやま こころの健康

kokoro no kenkou

2011 Vol. 53

特集 がんを抱えて生きること

シンポジウム

Re : ワーク

—職場のメンタルヘルスの視点から—



社団法人 岡山県精神保健福祉協会

<http://okayama-mental.jpn.org/>

第48回岡山県精神保健大会記念講演

「がんを抱えたときの心構え」

内 富 庸 介 先生



岡山大学大学院
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- ・サイコオンコロジー学会理事。

■がんを伝える

がんを抱えたときに、誰もが今心構えをしなければならない時代になりました。「がんを抱えたときの心構え」とタイトルしています。がんと心、心ががんという方向性もあるんですけど、今日は主にがんを抱えたときの心構えということをお話ししたいと思います。

がん告知ですけれども、やはり医師のほうは、若いときはそうでもないいでしょけれど、5年、10年、20年とキャリアを重ねていきますと、がんを伝えることが日々のことになってしまいますので、どうしても感情的にはならず冷静な顔で伝えている。一方、患者さん、ご家族にとっては、一生涯に1回もしくは2回あるかないかでしょうから、頭が真っ白になって、どうやって家に帰ったか分からないというほど、頭に、心に衝撃を与える事実です。このギャップが今少し問題になっていまして、あらかじめどういったギャップがあるのかということを知っておくことで備えるこ

とができる。

例えば、どんな強い人でも、不意におなかにパンチをくらうと、皆さんひっくり返りますよね。ですけど、あらかじめおなかに少し力を入れて、腹筋に力を入れるような形で備えておくと、ショックも和らぐ。そういったことを少しお話ししたいと思います。

インフォームド・コンセントという言葉が聞かれたことはおありでしょうか。どれぐらいいらっしゃいますか。かなりおられますね。これは「説明と同意」と訳されて日本に輸入されましたけど、よく見ると説明された上での同意なので、重要なのはやはり同意の部分です。

ですけど、こういったふうに訳されますと、医師が説明をして書面で同意を取れば、もう事足りて、次の治療が進むんじゃないかと思われる節があるんですけど、よくよく考えると、このインフォームド・コンセントも少し重要な問題をはらんでいます。

人の心の機能は「知情意」という言葉でよく表されます。知識の知、感情の情、そして意志・同意の意です。人の心はこの3つの言葉で表されるときに、この3つがいろんな関連をしながら最終的に同意という行動に表れるわけです。説明されるべき情報、がんに関する情報・知識で与えられますと、ほとんどの人で、最初のマンガではないですけど、動揺、衝撃、混乱、いろんな感情が出てきます。

この感情というのは、もともとどういった機能としてあるのか。人に限らず、情というのは、その方にとって与えられた事態・情報がプラスなのかマイナスなのか、大事なもののかそうでないのか、快なのか不快なのか、自分にとって得なのかそうでないのか。特に命にかかわるような問題ですと、衝撃を持って伝える、そして、衝撃を持って覚えておく、それが重要。

例えばへびを見て怖がる、そういう感情がない

と、その人はヘビにかまれてしまいますから、これは人間に限らずあらゆる生命に宿っている非常に重要なものです。説明される情報が大事なもののなか、そうでないのかという重み付けをするためには、感情というものは非常に重要になります。

説明「と」同意、知情意、このプロセスを並べてみますと、ここの「と」のところは実は抜けているのではないか、気持ちがすっぱり抜けているのではないかということがよくいわれます。これは患者さんの気持ちです。医師は説明をして同意を取るといふ日常生活に入ってしまうと、どうしても忘れがちなのが気持ちの部分です。

でも、この気持ちというのは、患者さんのいろいろなこれまでの人生の体験や価値観が非常に入った部分でありますので、特にこの感情を大事にしないと、次のがん医療、がん治療、がんの検査、どういふふうに同意していくのかというときに、患者さんの個々人の感情というのは非常に重要です。その感情はその方にしか分からない感情ですので、つらいのか、落ち込んだのか、不安なのか、または腹が立ったのか、そういった感情をできれば医師のほうに伝えてくださると、これからやってくるがん治療にどういふふうに向き合えばいいかというときの重要な手掛かりになります。

その方の人となり分かるということでは、感情を出すのはよくないですとか、そういったことをよくいわれるんですけど、どちらかという、出していただくほうが分かりやすい。どういふふうに進めばいいのかという道しるべになります。

特にがんは今、3人に1人、そのがんの診断直前からがんを疑う検査、1次検査で、「どうも精密検査の必要があるから、どこそこの病院に行って、精密検査を受けてください」という辺りから始まります。そして、がんの診断を受けると、ほとんどの人で自分はいったんは死ぬんじゃないか、どうしてあの人じゃなくて自分なんだというふうに思われます。

64万人、岡山市の人口に近いぐらいの方々が毎年がんと診断されます。これは、日本では2人に1人ががんという診断を受けていることになりま

す。3人に1人は不幸にしてがんと再発進行して、34万人の方、50%ぐらいの方が、がんで命を落とされます。3人に1人といいますと、皆さん、両隣の方の顔をもう一度見てください。恐らく近い将来……。

これだけ身近な病気でありますけど、がんと診断されたときは、症状で見つかる場合の方も多いですけど、検診がどんどん進んでいますので、ほとんどの方は症状がなく、写真に写って見つかります。ですので、どこも体が痛いことがないのに、「えっ、何で私が」という状況が非常に多くあります。そういった意味では、がんと診断されたときの問題は、ほとんどの場合は心の問題です。体の問題というよりは、心への圧倒的な衝撃になります。

そして、もう少しご紹介したいのは、34万人の方々が毎年亡くなられていまして、奥さん、ご主人を亡くされて喪に服しておられる方は20万人おられます。内訳を見ますと、男性が残る場合は5万人、女性が残る場合は15万人、すごい数の方々が生涯で最もつらい時期を経験されます。がんと診断されたときから、そういう日が来るであろうと思われる遺族の方、がんの闘病も長く、がんのあとの遺族としての生活も非常に長い。ある意味では、がん患者も家族も、お二人とも患者のような経験をされます。

このがんというものは、今どれぐらいの位置を占めているのかということ、ちょっと難しい数字になりますけど、少しご紹介します。これはWHO（世界保健機構）が全世界に、その国々で、どういった病気とその国の中で重要なものとして占められているかを示した障害調整生命年というのがあります。つまり、命としての数値と障害としての数値。つまり健康のロスと寿命としてのロス、両方とも損失になります。つまり、長生きできない場合も損失です。でも、長生きすればいいというものではなくて、不健康であれば、それもロスになります。それを合わせた数字として表したものが、このDALYという数値です。

日本では、今トップにある疾患が脳血管性の疾

特集 がんを抱えて生きること

患です。いわゆる脳卒中で、そのまま亡くなられた場合は、それだけで寿命のロスですけど、寝たきりになった場合は非常に長い健康ロス、健康寿命を失ったことになりますので、合わせると非常につらい疾患として、もちろん数も多いということもありますけど、非常に重要な疾患になっています。

2番目に認知症。3番目に単極性うつ病があります。4番目に心筋梗塞など虚血性の心疾患、そして5番目に自殺がきます。がんはもう少しあとになって、肺がん、胃がん、大腸がん。体のあちこちに出てきますから、1個1個は小さく見えます。そしてそううつ病、アルコール、統合失調症、そして乳がんがきます。

がんを総計で見ますと大体18%を占めます。精神疾患も合わせますと16%。心臓の血管疾患を合わせると15%。この3つの領域を合わせただけでも、日本の半分の不健康と寿命に貢献していることになるぐらい、非常に大きい疾患であります。

がんを抱えて自殺をされるとか、そういったことになると、非常に重要な位置を占めているのが、がん患者さんのメンタルヘルスです。今日お話しする内容は、がんを抱えたときの心構えということで、まず重要な部分として、説明と同意の間の気持ち、特に知情意の「情」の軌跡を知ろうということ、まず一緒に考えてみたいと思います。つまり、がんを抱えたらどういう気持ちになって、がんの診断、がんの闘病生活、そして自分らしく生きる、そういった3つのキーワードで、少しずつ振り返っていききたいと思います。

■がんとつき合っていく

これは、43歳の大腸がんの方が初めてがんと診断されたときの体験を振り返っておられたものを書いておられます。とても仕事に戻れるとは思っていませんでした。少し若い方ですと、がんはもう少し先の病気だと思っておられますが、40代だとまだまだ遠い将来じゃないかと思っておられる方がおられます。

でも、60代の方に聞くと、「いや、がんという

病気は70代だと思っていた」と。ところが、70代の方に聞くと、「あいつが元気なんだから、がんは80代の病気だと思っていた」と。皆さん、そういうふうな、少しずつがんに関する問題を先送りにされる傾向があるんですけど、少しこの40代のがん患者さんの話を振り返りたいと思います。

手術を受けた半年前を、遠い昔のように振り返る。軽い気持ちで受けた検診、そしてその後、驚天動地のがん告知、ためらう間もなく受けた手術。過剰なほどの回りのスタッフ、そして同じ病気のがん患者さんから、心の援助、いろいろな面での援助を受けて、ある種少し気分が高揚した躁状態のような入院生活だった。慌ただしく診断されてから手術まで来た。

そして、退院後1人になって襲ってきた死の恐怖。再発不安。退院すると、おうちに帰られて、周りの方々はみんな仕事に出て行かれますし、昼間にぽつんと残されるのが、家族がいなくなったおうち、家庭であります。1人になって初めて襲ってくる、振り返ると非常に怖い死の恐怖、再発不安。社会復帰してから痛感する、がん患者という烙印、疎外感。ひとりぼっちになってしまったような、そして、自分でも少し壁を作って、これまでの人間関係から少し距離を置いて、電話もなくなる。また掛けてこられなくなる。皆さん少し距離を感じられます。

そして、少しずつ溝を埋めていくまでに3年かかると言われていまして、がんを伝えられたときをがんの直下型大地震とすると、ほんとの意味での社会復帰まで含めると、大体3年かかります。3年の間、いろんなところで余震、再発不安が襲ってきます。

そのときに重要だった心構え、取った方策、家族や友人と共に集めたがんの知識を整理する、がんを抱えたあとの気持ちを打ち明ける、これこそ心の支援対策の第一歩だった。心を許せる同僚や家族の存在が何よりの助けだったと、振り返られました。

知情意でいうと知と情を周囲の方々に打ち明ける。いったん頭の中に入ったがんに関する知識。

多分、濃淡、重い軽い、重み付けは関係なく、頭の中にぐちゃぐちゃに入ります。それを、もう一度引き出しを開けて、周囲の方と一緒に、聞いてもらって整理するだけでずいぶん落ち着かれる方もいらっしゃいます。また、少し弱音が吐けるような部分もあれば、これまで行ってきたサークル活動ですとか、そこここで1人でも気持ちが打ち明けられると、ネットワークを失わずに、それまでの活動を失わずに。例えばおうちの中にも1人、職場にも1人、サークル活動の仲間にも1人、そうやってネットワークにそれぞれ1人サポーターを置くと、これまでの生活が維持できて非常に落ち着かれます。

いったん復帰の段階に入るときに、再発不安ということが1つ大きく向き合う課題になります。最初のがんの治療から1年間というのは、ある意味、体の機能の喪失。ほとんどのがん治療で、外科手術で胃を取ったり、腸を取ったり。体の機能を少し失いますので、非常に困った体の症状が残る。科学療法、放射線治療にしても、体のだるさは残ります。ですので、最初の治療から1年間というのは、体の機能の喪失からの回復に非常に時間をかける。体の機能を失ったことに対する精神的な後遺症、そしてそれと向き合いながら職場復帰をするという意味では、結構ストレスのかかる時期であります。

「仕事、できるんだろうか」「家事はほんとにできるのかしら」。そしてまた、がん患者ということで、職場から仕事をこれまでどおり与えてくれるんだろうか。そういった心配が頭をもたげます。そういったときも、先ほどと同じ、基本は同じです。身近な人に気持ちを打ち明けるといことが、心の体勢を整える意味では、非常に落ち着く第一歩であります。

再発不安の成り立ちは、多くのがんは、3年間は非常に再発する可能性が高い時期ですので、がんが再発するんじゃないか、地雷を踏むんじゃないか、ミサイルが飛んでくるんじゃないか。例えば腰が痛い、腰に転移したんじゃないか、咳が出ると、胸に転移したんじゃないか、頭痛がする

と、頭に転移したんじゃないか。そういったことで、いつもいつも、何かサインがあると、がんのこと、死のことを思い出す。地雷原にいるようだったと、よく3年間言われる方がいらっしゃいます。少し成り立ちを考えると、初めての水泳のときを思い出していただけると分かるかと思います。

例えば、がんも水泳と同じで初めての体験です。プールで練習するのと沖合で練習するのを比べてみてください。泳ぎをまったく知らない人、泳ぎ方を知らない人に、プールで練習して練習して、おうちへ帰られるのと、いきなり沖合でドボンとされて通院してくださいというのと、泳ぎ方が分からないという意味では、沖合でドボンとされるのは非常に不安が生じます。そういったちょっとしたことが再発不安につながります。

そして、従来はがんというと大体3ヶ月ぐらい入院するというのが一般的でした。入院している間に、いろんな心配事があれば、ドクターや看護師さんからいつも話が聞けるし、また、必ず退院前の先輩患者さんがいろんなことを教えてくれたり、同じ部屋の仲間が教えてくれたりという2~3ヶ月がありました。今は医療費抑制のために、2~3週間で、がんが治っても治らなくても、いったんは退院するという時代になってきました。

プールで3ヶ月泳ぐ練習をしてから退院だったのが、今は2~3週間程度の泳ぎ方でいきなり沖合に出されます。そういった意味では、家庭や職場での受け入れ体制づくり、やっぱり人の支えを求めていく、あらかじめこちら側が準備して、どんどん情報を交換しながら、気持ちを打ち明けたら、また患者会に参加したり、がん患者サロンに相談に行ったりというネットワークを自ら求めていくようなことをしない限り、なかなか沖合状態からプールに戻ることはできません。

そして、この3年を経ると、ようやくがんとの向き合い方も少し落ち着きを取り戻します。というのが、3年を過ぎると、大方のがんの再発する可能性はぐんと低くなります。病気の前と後、まったく同じ人生というのはなかなか難しいと思いますが、少しは病気の前夢だった、いつかはか

なうだろうな、どうなのかなと思っていたものの優先順位を上を上げて、今実行しようというふうに行動を変えられる方もいらっしゃる。また、体に自信がなくなった反面、心の側面では充実してきて、人生の意味とか、家庭や友人を大事にするとか、そういう心の面から見ると、3年もすると、がん患者さんはむしろ豊かになっておられる方がいます。帳尻を合わせると非常にうまく収まりだすのが3年ぐらいで、そこから人生の再設計を本格的に始められる方が多く見受けられます。

そういった生活の立て直し、気持ちの整理といったことを本に書かれた岸本葉子さんというエッセイストがいらっしゃるんですけど。この方も40代で思ってもみなかった大腸がんの進行がんを経験されて、3冊の本を書いておられます。最初に書かれたのが『がんから始まる』で、がんを体験したときの気持ちの側面を中心に書かれておられます。

そして、すぐにはなかなか自分ががんであること、また、がんを抱えて落ち込んだこと、不安になったことを周囲には打ち明けられなかった。この方はそのとき独身だったんですけど、10ヶ月ぐらいたってようやくがん患者会に行き、自分の体験を話して、ようやく周囲の人もみんな同じ体験をしているんだ、自分1人だけじゃないんだと、疎外感から少し克服できる手だてとして、自分と同じ体験をされた患者会で気持ちを打ち明けるといふことをされました。

その次に、これは一緒に本を書かせていただいたんですけど、がんに関する心の側面、体の側面の知識の整理。気持ちの次は、知識の整理。気持ちが落ち着いた段階で少しずつ知識の整理をされ、そして『四十でがんになってから』と、人生の再設計の本を書かれました。

これを整理しますと、いろんながんの知識を与えられますけど、最初は、情が非常に揺り動かされます。それが落ち着くプロセスとして、周囲の方に少しずつ気持ちの面を話しては整理する。そして、落ち着いてきてから、ようやく知識の整理をして、人生の再設計を行う。こういったプロセ

スが3年間かかるといわれています。

■心のケア

がん対策基本法が2007年にできました。がん患者さんの従来のケアというと、体の痛み一辺倒だったんですけど、体の緩和だけでなく、精神心理的な問題への援助、心の側面もがん患者さんに援助をしましょう。そして終末期、いわゆるがん細胞を壊して取り去る、そういう治療がなくなったときに、穏やかな生活を迎えるという緩和ケアのイメージがあったわけですけど、そうでなく、がん告知された段階から心のケアをしましょうという、初期段階からという言葉も入りました。

そして、患者のみならず、家族に対しても心のケアを。そして、岡山県、岡山市にもたくさんがん拠点病院はありますが、そこに緩和ケアチームを設置しましょう。この緩和ケアチームというのは、体の痛みを取る緩和ケア。そして、心の痛みに対応する精神科医、心療内科医を合わせて、精神腫瘍医と呼んでいます。

そして、緩和ケアチームの育成。在宅医療、地域における緩和ケアの教育や普及啓発。医師のコミュニケーション技術の向上。がん告知の在り方を変えましょうというようなことが、この基本計画で盛り込まれました。この基本計画をつくった委員の何人かは、実際のがん患者さんであり、ご遺族の方ですので、非常に患者目線に立った推進基本計画ができました。

精神腫瘍医というのは、非常にいかつい言葉なんですけど、腫瘍を抱えた患者さんを診る精神科医です。精神と腫瘍医。どんなことをするのかというと、これは、非常に精神科医の当たり前の基本的なことが中心であります。まず、カウンセリングというのは全員に行いますけど、まず、知識、情報を整理し、正しく理解するための援助を基本に行います。皆さん理解の仕方が違いますし、理解の深さ、広さが皆さん違いますので、その方にあった形の理解の仕方をまず援助します。

そして次に、支持的精神療法、もともとの回復法で乗り越えるための援助を行います。がんを抱