Original Article

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Validity on tentative design of a regional cooperation system for post-discharge perinatal grief care by the Delphi method

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Abstract

Loss of a child during the perinatal period due to stillbirth or neonatal death is likely to be accompanied by marked grief and the development of various health issues, which can result in inappropriate raising of the parents' other children. To improve post-discharge grief care, Yoneda et al. investigated the current state of such care in 2015, and reported the "post-discharge perinatal grief care and tentative design of a regional cooperation system."

The present study was performed to assess the validity of this tentative model for women that have lost a child during the perinatal period and their families, and to facilitate adoption of the model. The opinions of support systems (medical centers, administrative bodies, and self-help groups) were summarized using the Delphi method. Based on the model, a questionnaire consisting of 19 items regarding post-discharge support and cooperation was developed, and was administered twice to the subjects. An agreement rate of ≥ 51% was interpreted as representing the subjects' consensus, with rates of 51% – 69.9%, 70% – 79.9%, and ≥ 80% representing low, moderate, and strong agreement, respectively. In the first and second surveys, 82 and 65 completed questionnaires were collected, respectively. The level of agreement for 17 of the 19 items (89.4%) was moderate or strong (≥ 70%) , thus supporting the validity of the tentative model. The rates of agreement for "grief care principally provided by medical centers" and "collaboration following discharge" (appointment of persons in charge of grief care following discharge and coordination with relevant organizations, notification of perinatal deaths to administrative bodies, telephone calls/interviews following discharge, and interaction with self-help groups) were particularly high (≥ 80%). The administrative bodies did not agree regarding the management of support groups, and the agreement rate for regular telephone calls by medical centers was low. Through discussion the subjects' free comments and promoting cooperation among these three types of party based on the initiative of medical centers, it may be possible to increase the validity and facilitate the adoption of our model.

KEY WORDS

perinatal period grief care stillbirth and neonatal death cooperation system Delphi method

Introduction

As women can find considerable significance in being pregnant and delivering children, losing them during the perinatal period due to stillbirth or neonatal death can be greatly traumatic [1], and they are more likely to suffer from marked grief. In addition, they may develop various health issues [2-3], and raise their other children inappropriately [4-5]. Therefore, grief care is important to prevent health-related problems and inappropriate child-raising. In the U.S. and some European countries, in which advanced grief care is provided, the costs of grief care are covered by public funds or by insurance [6-10], while the Japanese government does not provide financial support for such care. It is necessary to develop systems unique to

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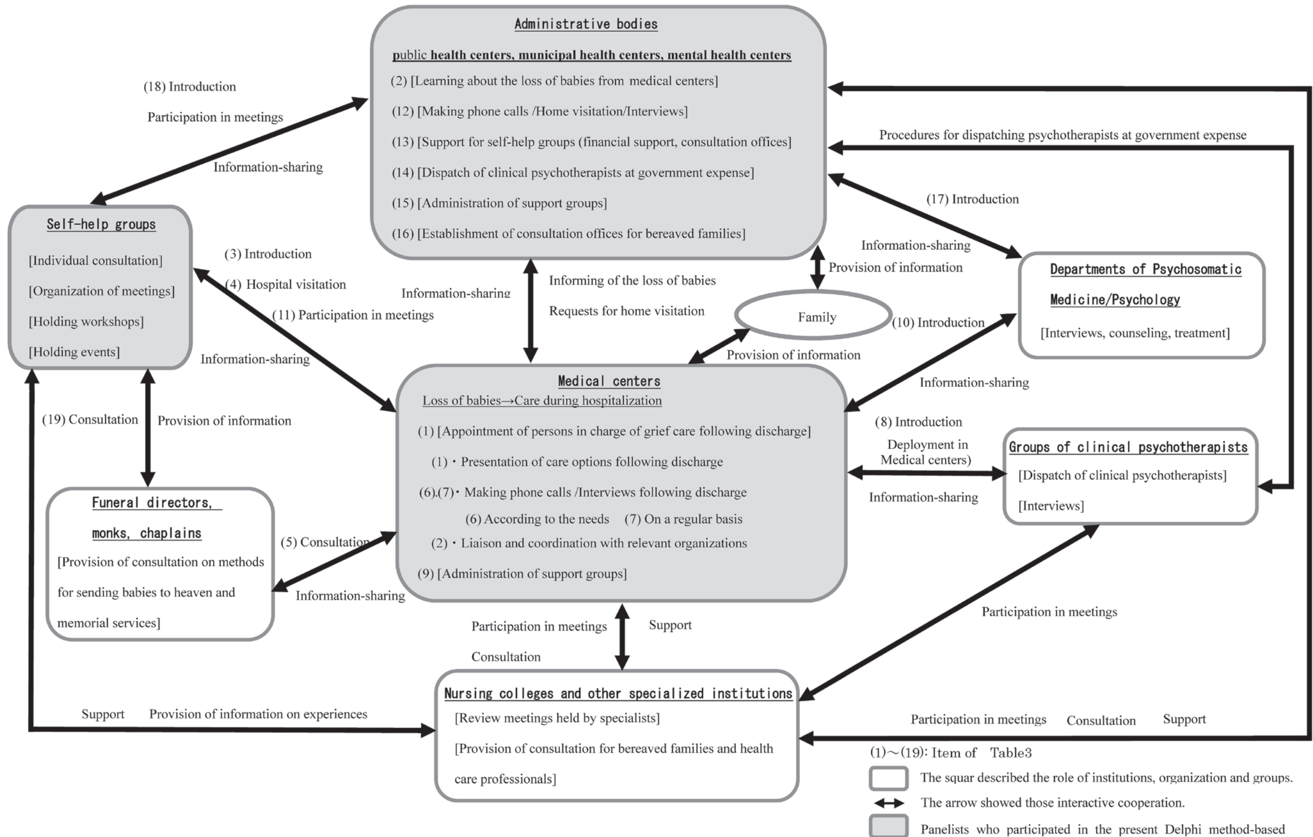
Japan while taking into consideration cultural and system differences between Japan and other countries. In Japan, since around 2008, books regarding perinatal grief care have been published [11-12], training programs concerning such care [13] have been implemented, and this type of care has been increasingly provided during hospitalization for childbirth. However, post-discharge regional care [14-17] and cooperation have been reported to be insufficient. In 2013, Yoneda et al. [18] surveyed medical centers (obstetrical departments, MFICU, and NICU), administrative bodies (health centers and municipalities), and self-help groups (including support groups [referred to as self-help groups]) throughout Japan to investigate the current state of and issues regarding post-discharge grief care and regional cooperation for women/families who had lost a child during the perinatal period. As a result, medical centers did not have systems facilitating the continued provision of grief care, and women were usually not followed after a consultation during a health checkup at one month post-delivery. The issues regarding grief care for administrative bodies included low-level awareness concerning the necessity of regional grief care, and those for self-help groups included weak relationships with medical centers and administrative bodies. On the basis of the results and cooperation-related proposals and requests made by these parties, a tentative model of post-discharge perinatal grief care and regional cooperation systems was designed (referred to as the tentative model) [Figure 1].

The present study aimed to assess the validity of the tentative model for females who have lost their child during the perinatal period, and opinions from supporters of those females were summarized using the Delphi method. I plan to further increase its validity to promote it, so that it will be adopted by a larger number of institutions. With this model, it may be possible to support women who have lost a child and are suffering from loneliness and grief in their community, and to help them and their families maintain health and appropriately raise their subsequent children.

Operational definition of terms

The perinatal grief care described in this study refers to



Figuer 1 Tentative design of a regional cooperation system model for perinatal grief care [17] Figuer8 partially modified

care provided from hospital admission until after discharge for women and their families who suffer from grief for loss of a child due to stillbirth or neonatal death. This care includes support for meeting with and separation from their children, and for overcoming their grief.

Methods

1. Survey period and research design

The study period was between March and October in 2015. The study employed the Delphi method, which facilitates the summarization and refinement of opinions obtained from a group of people. Using this method, questionnaire surveys regarding a certain theme are conducted multiple times. In any subsequent survey, the subjects are informed about the results of the previous survey, and asked to respond to the question items while reviewing these results. Thus, unlike face-to-face discussions to exchange opinions, this approach is not influenced by individuals' social status [19]. In the present study, people deemed likely to be providing support for individuals suffering from the perinatal death of a child were considered to belong to the same single group. Among this group, opinions from medical centers, administrative bodies, and self-help groups were summarized. Although psychologists, priests, and funeral directors had been included in the tentative model, they were not adopted as the subjects of the present study, because it would be difficult to obtain valid responses from them by implementing the Delphi method to solicit their opinions. When using the Delphi method, the opinion summary usually concludes after the third survey. However, in the present study, the first survey was a step in which a tentative cooperative model was designed based on the cooperation-related issues, proposals, and requests stated during our previous study by Japanese medical centers, administrative bodies, and self-help groups providing perinatal grief care [18], and questionnaire surveys were conducted twice using this model.

2. Subjects of the survey (selection of panelists)

To first facilitate the adoption of the tentative model in Prefecture I, 17 medical centers, 26 administrative bodies, and 19 self-help groups deemed likely to be providing grief care, particularly those from the prefecture, were requested to use the model. Because the number of self-help groups in the prefecture was low, those from other prefectures were also involved. The purpose of the study was explained to the nursing managers of the medical centers, mother-child health managers of the administrative bodies, and representatives of the self-help groups. The study subjects were then selected from or referred by those who provided consent. The subjects comprised the following individuals: an obstetrician, NICU physician, nurse whose main duty was to provide grief care, and nursing manager from each medical center; manager for mother-child healthcare and person in charge of such healthcare from each administrative body; and a representative and another member from each self-help group. Consent was obtained from 15 of the 17 medical centers (88.2%), 12 of the 26 administrative bodies (46.2%), and 14 of the 19 self-help groups (73.7%). The necessary documents were then handed or mailed to the subjects, and those who returned the questionnaire and agreement document served as panelists.

3. Outline of the questionnaire, and the methods of the first data collection

On the basis of the tentative model designed in the previous investigation [18], a questionnaire consisting of 19 items was developed; the 19 question sentences with detailed explanation involved post-discharge care, or care provided by medical centers and administrative bodies, and collaboration among medical centers, administrative bodies, self-help groups, specialists in psychosomatic internal medicine/psychiatrists, clinical psychotherapists, and funeral directors/priests. The numbers of the items of the tentative model were added to Figure 1. Each of the items regarding the validity of the model was rated using a five-point Likert-type scale (5: very useful, 1: not useful). Subjects were asked to make comments (e.g., reasons and alternatives) regarding the options they chose, and give opinions concerning model-related matters, including those in which the subjects were not involved. In addition, concerning subject attributes, the panelists from the medical centers and administrative bodies were asked about their age, sex, professional field, position, years of experience, and the unit to which they belonged. The panelists from the self-help groups were asked about their age, sex, position, profession, qualifications, and years of experience. The questionnaire, a study cooperation request form, agreement document, references used when responding to the questionnaire (cooperation-related issues, new proposals, and tentative models [18]), and self-addressed envelope were handed or mailed to the

subjects.

4. Methods for the second data collection

Subjects who participated in the first questionnaire survey (referred to as panelists) were asked to cooperate in the second survey. At this time, they were provided with the following information: 1) a graph of the first survey showing the distribution of opinions for each item regarding the usefulness of the model, 2) median values from each medical center, administrative body, and self-help group, 3) response values shown by the panelists in the first survey, and 4) free comments concerning each item. These comments included the opinions of subjects, their responses to the items of the first survey, and responses to any questions or doubts that they had during the survey. This information was also included in the questionnaire. Because no alternatives were proposed in the first survey, no additional information was included in any items of the second survey. As was the case with the first survey, in the second survey, 19 items were rated using a five-point Likert-type scale, and subjects were asked to make comments (e.g., reasons and opinions) regarding the options they chose.

5. Analysis methods

1) Analysis of the agreement rate

The agreement rates, which represent the subjects' degree of consensus, among all subjects and those of each (medical center, administrative bodies, and self-help) group in the first and second surveys were analyzed. As was the case in the study by Katoh [20], in the present study, agreement rates of 51% - 69.9%, 70% - 79.9%, and ≥ 80% were judged as representing low, moderate, and strong consensus, respectively, although different classifications had been adopted by previous studies [20-23].

2) Analysis of free comments as grounds for the agreement rate

The subjects' free comments for each item were summarized according to the type of party investigated (medical centers, administrative bodies, and self-help groups), and analyzed in a qualitative manner to identify grounds for the agreement rate and improvements in support/collaboration methods.

6. Ethical considerations

The representative of each party and the panelists filled out the study cooperation agreement document and study cooperation request form, respectively. The panelists were informed that their decisions would not be influenced by the representative of the party to which they belonged, non-participation in the study would not cause any demerits, withdrawal from the study was possible, and the identity of themselves and the party to which they belonged would be protected. A response to the questionnaire was interpreted as having consented to participate in the study. Because this study employed the Delphi method, the subjects' identities were encoded to protect their anonymity, and anonymized in a linkable manner using a conversion correspondence table.

This study was conducted with the approval of the medical ethics committee of Kanazawa University (No. 544-1).

Results

1. General information about the panelists

Consent was obtained from 15 medical centers, 12 administrative bodies, and 14 self-help groups. Among these parties, 82 and 65 panelists consented to participate in the first and second surveys, respectively. Table 1 shows the response rates and detailed information about the panelists, and Table 2 shows their characteristics (first survey).

2. Consensus about the tentative model of post-discharge perinatal grief care and regional cooperation systems (Table 3)

Details of each item are shown in Table 3. Thereafter, each item is represented in a simplified manner.

1) General consensus

The agreement rates among all subjects, including all groups (medical centers, administrative bodies, and self-help groups), for the following 13 items were high :

(1) "Appointment of persons in charge of grief care following discharge in medical centers", (2) "Notices of perinatal deaths by medical centers to administrative bodies", (3) "Introduce of self-help groups by medical centers", (5) "Collaboration between medical centers and funeral directors", (6) "Making phone calls and interviews by medical centers following discharge according to bereaved families' needs", (8) "Deployment clinical psychotherapists in medical centers", (10) "Introduce of psychologists by medical centers", (11) "Interaction between medical centers and self-help groups through participation in group-discussion meetings", (12) "Making phone calls, home visitation and interviews by administrative bodies", (13) "Support for self-help

Table 1　The response rates and detailed information about the panelists

		The number of requests		The number of participants		The response rates(%)	
		I	II	I	II	I	II
Total		135	82	82	65	60.7	79.3
Medical centers (15)	Total	54	35	35	27	78.3	77.1
	Doctor	12	2	2	2	16.7	100
	The nursing managers	19	15	15	13	78.9	86.7
	Nurse・Midwife	23	18	18	12	78.3	66.7
Administrative bodies (12)	Total	52	20	20	16	38.5	80.0
	Manager for mother-child healthcare	26	5	5	5	19.2	100
	Person in charge of mother-child healthcare	26	15	15	11	57.7	73.3
Self-help groups (14)	Total	29	27	27	22	93.1	81.5
	Representative	12	11	11	9	91.7	81.8
	Member	17	16	16	13	94.1	81.3

I : first survey　II : second survey

Table 2　The panelists characteristics（first survey）

		n	Age mean±SD (range) (year)	Years of experience in the current professional field Number of years participating in a self-help group mean±SD(year) (range) (year)	The number of men
Total		82			3
Medical centers	Total	35	46.2±9.6 (26-67)	19.3±10.3 (1-43)	2
	Doctor	2	51.0±23.7 (35-67)	26.5±23.3 (10-43)	2
	The nursing manager	18	52.8± 4.0 (47-59)	23.7± 8.8 (3-34)	0
	Nurse・Midwife	15	40.1± 7.6 (26-53)	14.7± 8.3 (1-30)	0
Administrative bodies	Total	20	41.2±11.1 (24-59)	17.2±12.0 (1-39)	0
	Manager for mother-child healthcare	5	56.2± 2.7 (53-59)	33.6±11.7 (29-39)	0
	Person in charge of mother-child healthcare	15	36.1± 7.6 (24-53)	11.7± 7.9 (1-28)	0
Self-help groups	Total	27	46.4± 6.1 (38-58)	8.8± 4.8 (1-19)	1
	Representative	11	47.5± 8.4 (40-58)	11.6± 5.2 (2-19)	1
	Member	16	45.6± 4.1 (38-53)	6.9± 3.5 (1-13)	0

groups by administrative bodies（financial support, consultation offices）”,（17）“Introduce of psychologists by administrative bodies”,（18）“Introduce of self-help groups by administrative bodies” and,（19）“Consultation for bereaved families/self-help groups by priests/funeral directors”.

A moderate agreement rate was generally achieved for the following 4 items :（4）“Hospital visitation by self-help groups”,（9）“Administration of support groups by medical centers”,（14）“Dispatch of clinical psychotherapists to medical centers at government expense” and（16）“Establishment of consultation offices for bereaved families by administrative bodies”. In general, the agreement rates were low for the item :（7）“Making phone calls following discharge on a regular basis by medical centers”, and the subjects did not agree to the item:（15）“Administration of support groups by administrative bodies”.

2）Comparison of the results of the first and second surveys

The agreement rates for the following two items :（2）“Notices of perinatal deaths by medical centers to administrative bodies” and（5）“Collaboration between medical centers and funeral directors” in the first and second surveys were moderate and high, respectively. The agreement rates for the following item :（4）“Hospital visitation by self-help groups” , in the first and second surveys were low and moderate, respectively. The agreement rates for the following item :（14）“Dispatch of clinical psychotherapists to medical centers at government expense” in the first and second surveys were high and moderate, respectively.

3）Comparison of medical centers, administrative bodies, and self-help groups

The agreement rate for（4）“Hospital visitation by self-help groups” was low only in the medical center group. The agreement rates for（14）“Dispatch of clinical psychotherapists to medical centers at government expense” and（16）“Establishment of consultation offices for bereaved families by administrative bodies” were low only in the administrative body group. The agreement rates for（12）“Making phone calls, home visitation and interviews by administrative bodies” was moderate only in the self-help group.

4）Influences due to differences in the backgrounds of the subjects

The responses were not influenced by differences in the backgrounds of the subjects, including the age, period of experience, type of job, position, and obstetrics or NICU.

Table 3 Consensus about the tentative model of post-discharge perinatal grief care and regional cooperation systems

The tentative model of post-discharge perinatal grief care and regional cooperation systems				n	Very useful	Quite useful	Useful	Not very useful	Not useful	Not sure	No answer given	The agreement rate(%)	*Category of the agreement rate
(1)	Medical centers should appoint staff members (groups) in charge of providing post-discharge grief care, present post-discharge care options to patients, and make necessary adjustments with relevant organizations	Ⅰ	Whole	82	23.2	35.4	32.9	4.9	2.4	0.0	1.2	91.5	strong
			Medical centers	35	11.4	40.0	42.9	5.7	0.0	0.0	0.0	94.3	strong
			Administrative bodies	20	15.0	55.0	25.0	0.0	5.0	0.0	0.0	95.0	strong
			Self-help groups	27	44.4	14.8	25.9	7.4	3.7	0.0	3.7	85.2	strong
		Ⅱ	Whole	65	24.6	41.5	27.7	3.1	1.5	0.0	1.5	93.8	strong
			Medical centers	27	11.1	55.6	29.6	3.7	0.0	0.0	0.0	96.3	strong
			Administrative bodies	16	6.3	56.3	25.0	0.0	6.3	6.3	0.0	87.5	strong
			Self-help groups	22	54.5	13.6	27.3	4.5	0.0	0.0	0.0	95.5	strong
(2)	Medical centers should make reports to administrative bodies about all cases of pediatric perinatal death occurring after issuing a mother-child handbook (staff members in charge of mother-child health in jurisdictional municipalities)	Ⅰ	Whole	82	20.7	17.1	36.6	22.0	2.4	1.2	0.0	74.4	moderate
			Medical centers	35	17.1	17.1	34.3	28.6	0.0	2.9	0.0	68.6	low
			Administrative bodies	20	15.0	10.0	35.0	35.0	5.0	0.0	0.0	60.0	low
			Self-help groups	27	29.6	22.2	40.7	3.7	3.7	0.0	0.0	92.6	strong
		Ⅱ	Whole	65	30.8	24.6	36.9	6.2	1.5	0.0	0.0	92.3	strong
			Medical centers	27	25.9	29.6	37.0	7.4	0.0	0.0	0.0	92.6	strong
			Administrative bodies	16	25.0	25.0	37.5	6.3	6.3	0.0	0.0	87.5	strong
			Self-help groups	22	40.9	18.2	36.4	4.5	0.0	0.0	0.0	95.5	strong
(3)	Medical centers should introduce a self-help group to those who have lost a child using brochures about the group, and cooperate with the group by telephone if these people desire so	Ⅰ	Whole	82	24.4	28.0	36.6	8.5	1.2	1.2	0.0	89.0	strong
			Medical centers	35	11.4	34.3	37.1	17.1	0.0	0.0	0.0	82.9	strong
			Administrative bodies	20	10.0	40.0	45.0	0.0	0.0	5.0	0.0	95.0	strong
			Self-help groups	27	51.9	11.1	29.6	3.7	3.7	0.0	0.0	92.6	strong
		Ⅱ	Whole	65	23.1	26.2	46.2	3.1	0.0	0.0	1.5	95.4	strong
			Medical centers	27	18.5	29.6	44.4	7.4	0.0	0.0	0.0	92.6	strong
			Administrative bodies	16	6.3	31.3	56.3	0.0	0.0	0.0	6.3	93.8	strong
			Self-help groups	22	40.9	18.2	40.9	0.0	0.0	0.0	0.0	100.0	strong
(4)	If desired by a hospitalized person who has lost a child, medical centers should ask members of a self-help group to visit the person and share their experience	Ⅰ	Whole	82	12.2	19.5	29.3	26.8	9.8	0.0	2.4	61.0	low
			Medical centers	35	0.0	5.7	31.4	42.9	17.1	0.0	2.9	37.1	zero
			Administrative bodies	20	10.0	45.0	40.0	5.0	0.0	0.0	0.0	95.0	strong
			Self-help groups	27	29.6	18.5	18.5	22.2	7.4	0.0	3.7	66.7	low
		Ⅱ	Whole	65	12.3	18.5	40.0	24.6	4.6	0.0	0.0	70.8	moderate
			Medical centers	27	3.7	18.5	44.4	29.6	3.7	0.0	0.0	66.7	low
			Administrative bodies	16	6.3	25.0	43.8	25.0	0.0	0.0	0.0	75.0	moderate
			Self-help groups	22	27.3	13.6	31.8	18.2	9.1	0.0	0.0	72.7	moderate
(5)	Medical centers should join bereaved families to listen to explanations of procedures for the funeral ceremony provided by funeral directors, and support the families according to their needs	Ⅰ	Whole	82	22.0	24.4	29.3	20.7	3.7	0.0	0.0	75.6	moderate
			Medical centers	35	11.4	22.9	40.0	20.0	5.7	0.0	0.0	74.3	moderate
			Administrative bodies	20	20.0	30.0	30.0	20.0	0.0	0.0	0.0	80.0	strong
			Self-help groups	27	37.0	22.2	14.8	22.2	3.7	0.0	0.0	74.1	moderate
		Ⅱ	Whole	65	18.5	24.6	40.0	13.8	3.1	0.0	0.0	83.1	strong
			Medical centers	27	14.8	25.9	33.3	18.5	0.6	0.0	0.0	74.1	moderate
			Administrative bodies	16	12.5	25.0	56.3	6.3	0.0	0.0	0.0	93.8	strong
			Self-help groups	22	27.3	22.7	36.4	13.6	0.0	0.0	0.0	86.4	strong
(6)	After discharge, medical centers should contact those who have lost a child by telephone, send staff members to their residence, and provide them with consultations according to their needs	Ⅰ	Whole	82	25.6	45.1	25.6	1.2	1.2	1.2	0.0	96.3	strong
			Medical centers	35	17.1	48.6	31.4	2.9	0.0	0.0	0.0	97.1	strong
			Administrative bodies	20	25.0	45.0	25.0	0.0	0.0	5.0	0.0	95.0	strong
			Self-help groups	27	37.0	40.7	18.5	0.0	3.7	0.0	0.0	96.3	strong
		Ⅱ	Whole	65	26.2	44.6	29.2	0.0	0.0	0.0	0.0	100.0	strong
			Medical centers	27	18.5	51.9	29.6	0.0	0.0	0.0	0.0	100.0	strong
			Administrative bodies	16	12.5	50.0	37.5	0.0	0.0	0.0	0.0	100.0	strong
			Self-help groups	22	45.5	31.8	22.7	0.0	0.0	0.0	0.0	100.0	strong
(7)	Medical centers should regularly contact women and their families who have lost a child by telephone , even when they have not contacted the hospital since discharge	Ⅰ	Whole	82	7.3	18.3	37.8	31.7	3.7	1.2	0.0	63.4	low
			Medical centers	35	2.9	11.4	48.6	31.4	2.9	2.9	0.0	62.9	low
			Administrative bodies	20	5.0	25.0	20.0	50.0	0.0	0.0	0.0	50.0	zero
			Self-help groups	27	14.8	22.2	37.0	18.5	7.4	0.0	0.0	74.1	moderate
		Ⅱ	Whole	65	3.1	13.8	46.2	36.9	0.0	0.0	0.0	63.1	low
			Medical centers	27	0.0	11.1	55.6	33.3	0.0	0.0	0.0	66.7	low
			Administrative bodies	16	0.0	6.3	43.8	50.0	0.0	0.0	0.0	50.0	zero
			Self-help groups	22	9.1	22.7	36.4	31.8	0.0	0.0	0.0	68.2	low

*strong: 80%～ moderate: 70～79.9% low: 51～69.9% zero: ～50%

	The tentative model of post-discharge perinatal grief care and regional cooperation systems			n	Very useful	Quite useful	Useful	Not very useful	Not useful	Not sure	No answer given	The agreement rate(%)	Category of the agreement rate
(8)	Medical centers should deploy clinical psychotherapists in the institution to provide consultation services	I	Whole	82	31.7	30.5	28.0	7.3	2.4	0.0	0.0	90.2	strong
			Medical centers	35	20.0	34.3	31.4	14.3	0.0	0.0	0.0	85.7	strong
			Administrative bodies	20	35.0	35.0	25.0	0.0	5.0	0.0	0.0	95.0	strong
			Self-help groups	27	44.4	22.2	25.9	3.7	3.7	0.0	0.0	92.6	strong
		II	Whole	65	30.8	29.2	30.8	6.2	1.5	0.0	1.5	90.8	strong
			Medical centers	27	22.2	37.0	33.3	7.4	0.0	0.0	0.0	92.6	strong
			Administrative bodies	16	43.8	25.0	18.8	0.0	6.3	0.0	6.3	87.5	strong
			Self-help groups	22	31.8	22.7	36.4	9.1	0.0	0.0	0.0	90.9	strong
(9)	Support groups should be managed mainly by medical centers	I	Whole	82	12.2	17.1	45.1	19.5	3.7	0.0	2.4	74.4	moderate
			Medical centers	35	8.6	5.7	45.7	28.6	5.7	0.0	5.7	60.0	low
			Administrative bodies	20	5.0	40.0	50.0	5.0	0.0	0.0	0.0	95.0	strong
			Self-help groups	27	22.2	14.8	40.7	18.5	3.7	0.0	0.0	77.8	moderate
		II	Whole	65	12.3	13.8	52.3	20.0	0.0	0.0	1.5	78.5	moderate
			Medical centers	27	11.1	3.7	59.3	25.9	5.7	0.0	5.7	74.1	moderate
			Administrative bodies	16	6.3	25.0	62.5	0.0	0.0	0.0	6.3	93.8	strong
			Self-help groups	22	18.2	18.2	36.4	27.3	0.0	0.0	0.0	72.7	moderate
(10)	When psychologists' intervention is required as viewed by medical centers, the centers should refer patients to psychologists according to the requests of the patients	I	Whole	82	26.8	35.4	34.1	2.4	1.2	0.0	0.0	96.3	strong
			Medical centers	35	22.9	31.4	45.7	0.0	0.0	0.0	0.0	100.0	strong
			Administrative bodies	20	25.0	45.0	30.0	0.0	0.0	0.0	0.0	100.0	strong
			Self-help groups	27	33.3	33.3	22.2	7.4	3.7	0.0	0.0	88.9	strong
		II	Whole	65	27.7	35.4	35.4	1.5	0.0	0.0	0.0	98.5	strong
			Medical centers	27	29.6	29.6	40.7	0.0	0.0	0.0	0.0	100.0	strong
			Administrative bodies	16	18.8	43.8	37.5	0.0	0.0	0.0	0.0	100.0	strong
			Self-help groups	22	31.8	36.4	27.3	4.5	0.0	0.0	0.0	95.5	strong
(11)	Professionals from medical centers should participate in self-help group discussions to understand the experience of those who have lost a child and answer technical questions (interaction with self-help groups)	I	Whole	82	20.7	35.4	32.9	8.5	1.2	1.2	0.0	89.0	strong
			Medical centers	35	8.6	42.9	31.4	17.1	0.0	0.0	0.0	82.9	strong
			Administrative bodies	20	15.0	30.0	50.0	5.0	0.0	0.0	0.0	95.0	strong
			Self-help groups	27	40.7	29.6	22.2	0.0	3.7	3.7	0.0	92.6	strong
		II	Whole	65	21.5	43.1	26.2	6.2	1.5	0.0	1.5	90.8	strong
			Medical centers	27	3.7	59.3	29.6	7.4	0.0	0.0	0.0	92.6	strong
			Administrative bodies	16	12.5	31.3	43.8	6.3	0.0	0.0	6.3	87.5	strong
			Self-help groups	22	50.0	31.8	9.1	4.5	4.5	0.0	0.0	90.9	strong
(12)	Administrative bodies should contact those who have lost a child by telephone, send staff members to their residence, and provide them with consultations according to their needs	I	Whole	82	11.0	26.8	46.3	12.2	1.2	1.2	1.2	84.1	strong
			Medical centers	35	11.4	34.3	45.7	5.7	0.0	0.0	2.9	91.4	strong
			Administrative bodies	20	15.0	30.0	45.0	10.0	0.0	0.0	0.0	90.0	strong
			Self-help groups	27	7.4	14.8	48.1	22.2	3.7	3.7	0.0	70.4	moderate
		II	Whole	65	13.8	21.5	47.7	9.2	0.0	0.0	7.7	83.1	strong
			Medical centers	27	18.5	22.2	44.4	0.0	0.0	0.0	14.8	85.2	strong
			Administrative bodies	16	12.5	18.8	56.3	6.3	0.0	0.0	6.3	87.5	strong
			Self-help groups	22	9.1	22.7	45.5	22.7	0.0	0.0	0.0	77.3	moderate
(13)	Administrative bodies should support self-help groups (providing activity-related consultations and financial support)	I	Whole	82	32.9	19.5	36.6	6.1	2.4	1.2	1.2	89.0	strong
			Medical centers	35	31.4	20.0	45.7	0.0	0.0	0.0	2.9	97.1	strong
			Administrative bodies	20	0.0	25.0	50.0	15.0	5.0	5.0	0.0	75.0	moderate
			Self-help groups	27	59.3	14.8	14.8	7.4	3.7	0.0	0.0	88.9	strong
		II	Whole	65	38.5	15.4	33.8	1.5	1.5	0.0	9.2	87.7	strong
			Medical centers	27	29.6	18.5	37.0	0.0	0.0	0.0	14.8	85.2	strong
			Administrative bodies	16	12.5	12.5	56.3	0.0	6.3	0.0	12.5	81.3	strong
			Self-help groups	22	68.2	13.6	13.6	4.5	0.0	0.0	0.0	95.5	strong
(14)	Administrative bodies should dispatch clinical psychotherapists to medical centers at public expense on an as-required basis	I	Whole	82	23.2	24.4	32.9	12.2	3.7	2.4	1.2	80.5	strong
			Medical centers	35	25.7	25.7	45.7	0.0	0.0	0.0	2.9	97.1	strong
			Administrative bodies	20	0.0	20.0	30.0	30.0	15.0	5.0	0.0	50.0	zero
			Self-help groups	27	37.0	25.9	18.5	14.8	0.0	3.7	0.0	81.5	strong
		II	Whole	65	20.0	29.2	27.7	12.3	1.5	0.0	9.2	76.9	moderate
			Medical centers	27	18.5	33.3	29.6	3.7	0.0	0.0	14.8	81.5	strong
			Administrative bodies	16	6.3	25.0	31.3	18.8	6.3	0.0	12.5	62.5	low
			Self-help groups	22	31.8	27.3	22.7	18.2	0.0	0.0	0.0	81.8	strong

*strong: 80%～ moderate: 70～79.9% low: 51～69.9% zero: ～50%

The tentative model of post-discharge perinatal grief care and regional cooperation systems				n	Very useful	Quite useful	Useful	Not very useful	Not useful	Not sure	No answer given	The agreement rate(%)	Category of the agreement rate
(15)	Support groups should be managed mainly by administrative bodies	Ⅰ	Whole	82	6.1	6.1	39.0	36.6	7.3	2.4	2.4	51.2	low
			Medical centers	35	5.7	11.4	62.9	14.3	0.0	0.0	5.7	80.0	strong
			Administrative bodies	20	0.0	0.0	25.0	50.0	20.0	5.0	0.0	25.0	zero
			Self-help groups	27	11.1	3.7	18.5	55.6	7.4	3.7	0.0	33.3	zero
		Ⅱ	Whole	65	6.2	7.7	33.8	40.0	4.6	0.0	7.7	47.7	zero
			Medical centers	27	7.4	11.1	48.1	18.5	0.0	0.0	14.8	66.7	low
			Administrative bodies	16	0.0	6.3	25.0	50.0	12.5	0.0	6.3	31.3	zero
			Self-help groups	22	9.1	4.5	22.7	59.1	4.5	0.0	0.0	36.4	zero
(16)	Administrative bodies should appoint staff members providing consultations for those who have lost a child	Ⅰ	Whole	82	11.0	19.5	42.7	9.8	4.9	2.4	9.8	73.2	moderate
			Medical centers	35	14.3	22.9	40.0	2.9	0.0	0.0	20.0	77.1	moderate
			Administrative bodies	20	0.0	15.0	50.0	15.0	15.0	5.0	0.0	65.0	low
			Self-help groups	27	14.8	18.5	40.7	14.8	3.7	3.7	3.7	74.1	moderate
		Ⅱ	Whole	65	13.8	18.5	43.1	12.3	3.1	0.0	9.2	75.4	moderate
			Medical centers	27	18.5	18.5	40.7	7.4	0.0	0.0	14.8	77.8	moderate
			Administrative bodies	16	0.0	12.5	50.0	25.0	6.3	0.0	6.3	62.5	low
			Self-help groups	22	18.2	22.7	40.9	9.1	4.5	0.0	4.5	81.8	strong
(17)	When psychologists' intervention is required as viewed by administrative bodies, they should refer bereaved families to psychologists according to the requests of the patients	Ⅰ	Whole	82	19.5	41.5	34.1	1.2	1.2	1.2	1.2	95.1	strong
			Medical centers	35	20.0	34.3	40.0	2.9	0.0	0.0	2.9	94.3	strong
			Administrative bodies	20	15.0	60.0	20.0	0.0	5.0	0.0	0.0	95.0	strong
			Self-help groups	27	22.2	37.0	37.0	0.0	0.0	3.7	0.0	96.3	strong
		Ⅱ	Whole	65	16.9	41.5	30.8	3.1	1.5	0.0	6.2	89.2	strong
			Medical centers	27	22.2	37.0	25.9	0.0	0.0	0.0	14.8	85.2	strong
			Administrative bodies	16	12.5	56.3	25.0	0.0	6.3	0.0	0.0	93.8	strong
			Self-help groups	22	13.6	36.4	40.9	9.1	0.0	0.0	0.0	90.9	strong
(18)	Administrative bodies should introduce a self-help group to those who have lost a child using brochures about the group, and cooperate with the group by telephone if these people desire so	Ⅰ	Whole	82	29.3	28.0	34.1	4.9	2.4	0.0	1.2	91.5	strong
			Medical centers	35	17.1	28.6	42.9	8.6	0.0	0.0	2.9	88.6	strong
			Administrative bodies	20	20.0	40.0	30.0	5.0	5.0	0.0	0.0	90.0	strong
			Self-help groups	27	51.9	18.5	25.9	0.0	3.7	0.0	0.0	96.3	strong
		Ⅱ	Whole	65	27.7	13.8	43.1	7.7	1.5	0.0	6.2	84.6	strong
			Medical centers	27	22.2	11.1	48.1	3.7	0.0	0.0	14.8	81.5	strong
			Administrative bodies	16	6.3	18.8	56.3	12.5	6.3	0.0	0.0	81.3	strong
			Self-help groups	22	50.0	13.6	27.3	9.1	0.0	0.0	0.0	90.9	strong
(19)	Priests/funeral directors should provide mental support, including attitudes to comfort the spirits of the deceased, at the requests of bereaved families/self-help groups	Ⅰ	Whole	82	19.5	34.1	31.7	7.3	3.7	0.0	3.7	85.4	strong
			Medical centers	35	20.0	25.7	42.9	5.7	2.9	0.0	2.9	88.6	strong
			Administrative bodies	20	0.0	50.0	35.0	5.0	0.0	0.0	10.0	85.0	strong
			Self-help groups	27	33.3	33.3	14.8	11.1	7.4	0.0	0.0	81.5	strong
		Ⅱ	Whole	65	18.5	30.8	32.3	7.7	3.1	0.0	7.7	81.5	strong
			Medical centers	27	22.2	18.5	29.6	7.4	7.4	0.0	14.8	70.4	moderate
			Administrative bodies	16	0.0	43.8	43.8	6.3	0.0	0.0	6.3	87.5	strong
			Self-help groups	22	27.3	36.4	27.3	9.1	0.0	0.0	0.0	90.9	strong

*strong: 80%～ moderate: 70～79.9% low: 51～69.9% zero: ～50%

3. Free comments as grounds of the agreement rate

According to the subjects' free comments, supporters from medical centers, administrative bodies, self-help groups, and clinical psychotherapists need to be highly professional in grief care in order to facilitate the adoption of our model. To analyze points to be improved regarding the tentative model, subjects' opinions as grounds for the agreement rate (particularly those concerning items with a zero to moderate agreement rate) are shown below:

Concerning the item (2) "Notices of perinatal deaths by medical centers to administrative bodies", in the first survey, medical centers and administrative bodies showed a low agreement rate because of opinions that such cases must be clarified by these bodies based on stillbirth reports and death certificates, and that it is difficult for the bodies to support those who have lost a child. However, in the second survey, when the subjects from the medical centers and administrative bodies were informed that these bodies have difficulty clarifying cases of pediatric perinatal death, and that they should avoid causing emotional discomfort for those who have lost a child by contacting them, a high agreement rate was achieved. Regarding the item (4) "Hospital visitation by self-help groups", subjects generally considered that systems that meet the needs of people having such a desire should be developed; however, medical centers showed a low agreement rate because of opinions that visiting these people during hospitalization is too early, and that it is difficult to arrange such opportunities. If collaboration between medical centers and self-help groups are promoted, including their participation in talk sessions, members of self-help groups will be able to visit the inpatients. Subjects from self-help groups also felt anxious about interacting with such people. Concerning the item (7) "Making phone calls following discharge on a regular basis by medical centers" , there was an opinion that these women/families should be addressed according to their needs because such contacts and visits may not be beneficial for them depending on their relationship with the hospital, and the agreement rate was low. As alternatives to this, providing a consultation at discharge and sending letters were proposed. Regarding the item (9) "Administration of support groups by medical centers", there was an opinion that people who have lost a child can consult medical staff who know about their history. On the other hand, subjects stated that it may be hard for people who have lost a child to visit the same hospital, and that it is difficult to continue managing support groups at medical centers. As an alternative to such groups, subjects suggested that self-help groups should support these people in cooperation with administrative bodies while giving consideration to the location of support activities. Concerning the item (12) "Making phone calls, home visitation and interviews by administrative bodies", subjects were concerned that such staff members may not fully understand the history of those who have lost a child, and that they may address these people in a non-empathetic manner or lack knowledge and skills regarding grief care. In particular, self-groups showed a moderate agreement rate for this item. Regarding the item (15) "Administration of support groups by administrative bodies", subjects stated that, although individuals who have lost a child would achieve senses of relief and trust if administrative bodies lead support groups, it is better for these bodies to aid self-help groups because the number of such individuals is low and it is difficult for these bodies to support them due to a lack of manpower. Therefore, the subjects did not agree on the suggestion. Concerning the item (16) "Establishment of consultation offices for bereaved families by administrative bodies", whilst subjects took the view that appointing such staff members is important to refer these individuals to self-help groups, subjects from administrative bodies disagreed with the item because of the possibility that such support may not be required as much. Whereas the agreement rate for (14) "Dispatch of clinical psychotherapists to medical centers at government expense" was high among medical centers and self-help groups (large numbers of subjects in these groups requested it) , the agreement rate among administrative bodies was low because it is difficult for them to acquire budgets.

Discussion

1. The validity of the tentative model

Of the 19 items regarding the usefulness of our model, high, moderate, low, and zero agreement rates were achieved for 13 (68.4%) , 4 (21.0%) , 1 (5.2%) , and 0 (5.2%) , respectively, with the rate being ≥ 70% for 17 items (89.4%) . Thus, for more than 90% of the items, a moderate or stronger consensus was obtained. It may be possible to increase the validity of the tentative model through discussing the opinions given on the items for

which a moderate rate was achieved.

2. Validity of systems enabling medical centers to lead the provision of post-discharge grief care

High agreement rates were achieved for the item stating that medical centers should appoint staff members in charge of post-discharge grief care, make necessary reports to administrative bodies, cooperate with self-help groups, and continue providing post-discharge support (contacting those who have lost a child by telephone, sending medical staff to their residence, and providing them with consultations). In addition, some subjects commented that individuals who have lost a child will be more likely to achieve a sense of relief and feel comfortable consulting healthcare workers if these workers begin to learn about the history of these individuals during hospitalization and interact with them until after discharge. This comment indicates that these subjects generally agreed with the view that it is ideal to develop systems enabling medical centers to continue intervening for people who have lost a child. The authors suggest that, to reduce the grief care-related burden on medical centers, there is a need to develop systems with which those who have lost a child can be followed by hospital teams instead of by individual hospital staff members, lessen the financial burden on these centers and maintain their manpower by establishing specialized outpatient units (e.g., those for grief care)[24), and ensure sufficient human resources providing such care.

In addition, the authors propose that: 1) the timing of contacting people who have lost a child by telephone and visiting them should be determined according to their individuality, 2) there is a need to develop ideas regarding how to address them (e.g., sending them letters), and 3) self-help group members with a similar experience may be able to intervene for them depending on the relationship between the hospital and group.

3. Grief care that must be provided by administrative bodies

Few people from administrative bodies participated in the study as panel members presumably because the rate of perinatal death rate is very low in some areas. However, this did not influence the results or cause any significant bias. Administrative bodies may need to receive reports from medical centers on all cases of pediatric neonatal death that occur after issuing a mother-child handbook. Although it may be necessary to encourage cooperation among such bodies, it may be extremely important for them to clarify the occurrence of perinatal death and avoid unnecessary contacts in order not to cause emotional discomfort. For this purpose, it is imperative to discuss how to establish systems enabling administrative bodies to be informed by medical centers about cases of perinatal death.

For the item stating that administrative bodies support individuals who have lost a child by means of telephone calls, visitations, and consultations, both these bodies and medical centers showed a high agreement rate, but self-help groups showed a moderate agreement rate. These results suggest that self-help groups perceive difficulty in establishing a relationship with administrative bodies, and are concerned about a lack of skills for the above-mentioned types of support. Although administrative bodies perceived the need for these types of support, as indicated by the high agreement rate, free comments from these bodies suggest that they are concerned about insufficient manpower and staff members' lack of skills, and that they generally have negative attitudes towards grief care. On this basis, the authors propose that, in cooperation with medical centers and psychologists, administrative bodies should generally act as an intermediary between self-help groups and people who have lost a child, and support the activities of these groups (provision of venues and financial aid).

4. Necessity for self-help groups to make suggestions to medical centers and administrative bodies

The rate of agreement to medical centers' participation in talk sessions held by self-help groups was high among all three parties. Making a suggestion, to medical centers, of the development of a system to promote their regular participation in the sessions will encourage their interaction with self-help groups. Although the rate of agreement to visits to inpatients by members of self-help groups was low among the subjects of the medical center group, the development of the system may promote the visitation. The rate of agreement to administrative bodies' support for self-help groups was also high, which suggests that it is necessary to actively consult administrative bodies to maintain the activities of self-help groups.

5. Comparison with grief care and models in other countries

People in Western countries can receive grief care at public expense or under health insurance as explained

in the preceding paragraphs. Some Western countries have national organizations that provide bereaved families with care. Furthermore, as another significant difference from Japan, costs of training volunteers involved in grief support and grief care expenses are covered by donations in those countries[6-10]. Furthermore, there are also cultural differences in the grieving process[25-26]. Therefore, it is important to develop models according to the uniqueness of Japanese society and culture, rather than using models of the Western systems. In this sense, the present study has provided knowledge required for the development of such models.

Conclusion

Among the 19 items regarding the tentative model of post-discharge perinatal grief care and regional cooperation systems, the agreement rate was 70% or higher for 17 items (89.4%), which supports the validity of the tentative model. The agreement rate was particularly high (≥ 80%) for grief care and post-discharge collaboration, primarily conducted by medical centers. Through discussion the subjects' free comments and promoting cooperation among these three types of party based on the initiative of medical centers, it may be possible to increase the validity of the tentative model and facilitate the adoption of our model.

Limitations and Challenges for the Future

Subjects from all parties investigated (medical centers, administrative bodies, self-help groups, and clinical psychotherapists) stated that grief care for people who have lost a child must be provided by highly-professional staff members as their supporters, and that this is a precondition for establishing systems that provide grief care-related education and support staff members providing such education. In addition to the development of such systems, there is a need to help staff members improve their skills for grief care[27].

In the present study, it was possible to request cooperation from medical centers and administrative bodies deemed likely to be providing perinatal grief care, particularly centers and bodies in Prefecture I. However, because the number of self-help groups in the prefecture was not sufficient, those from throughout Japan were involved in this study; therefore, the possibility that the subjects' opinions may not represent the situation of the prefecture cannot be denied. To adopt the tentative model successfully, it may be necessary to make some adjustments according to the situation of each community. As a limitation, the opinions of psychologists, priests, and funeral directors included in the tentative model have not been reflected in the results of the present study. Since medical centers, administrative bodies, and self-help groups did not disagree with their positions as relevant professionals, as suggested in the tentative model, in their responses, it will be necessary to coordinate their opinions, so that they will be reflected in the model.

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Conflict of interest

The authors do not have a conflict of interest (COI) with any operator.

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デルファイ法による退院後の周産期のグリーフケアと地域連携システムモデル試案の妥当性の検討

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要　　旨

周産期の児との死別（死産・新生児死亡）は、悲嘆が複雑化しやすく、様々な健康障害を生じたり、残されたきょうだいに対する不適当な養育につながることが明らかになっている。米田らは施設退院後のグリーフケアの充実を目的に実態調査を行い、2015 年に「退院後の周産期のグリーフケアと地域連携システムモデル試案」を作成した。今回、このモデル試案が周産期の死を経験した母親・家族にとって妥当であるか、支援関係者である医療施設・行政・自助グループの方々を対象にデルファイ法を用いて意見を集約し、導入に向けて検討することを目的とした。モデル試案をもとに作成した退院後の支援内容と連携内容 19 項目の妥当性について質問紙調査を 2 回実施した。同意率は 51％以上に設定し、51 ～ 69.9％を低い、70 ～ 79.9％を中等度、80％以上を高い同意率とした。第 1 回調査 82 名、第 2 回調査 65 名から返信があり、中等度（70％）以上の同意率を得たものは 19 項目中 17 項目（89.4％）であり、概ねモデル試案が妥当であることが示唆された。特に医療施設が核になって実施するグリーフケアと退院後の連携（退院後のグリーフケア担当者の決定と関係機関との連絡調整、行政へ周産期の死の連絡、退院後の電話訪問･面談、自助グループとの交流）は高い同意率（80％以上）が得られた。今後は医療施設を核として、フリーコメントに書かれていた意見を加味し､3 者の連携を高めていくことによって､より一層モデル試案の妥当性を高めることができ､導入に近づけていくことができると考えられる。