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Original Article

Post-discharge perinatal grief care and tentative design of a regional cooperation system

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Abstract

Women that have lost a child during the perinatal period are more likely to continue suffering from deep loneliness and grief after discharge. Here, a survey was performed among perinatal medical centers, health centers, municipal centers, and self-help groups throughout Japan to clarify the current state and issues regarding post-discharge grief care and regional cooperation, and to design a tentative regional cooperation system model for perinatal grief care. A total of 475 facilities provided effective responses to our self-completed questionnaire. These data were subjected to descriptive and qualitative content analyses, which revealed that sufficient grief care was not provided for post-discharge women and their families. In addition, a tentative regional cooperation model was designed based on the current state and issues regarding regional cooperation. This cooperation model included "assignment of those in charge of post-discharge grief care in medical centers","development of a system to report pediatric deaths from medical centers to administrative bodies","assignment of clinical psychologists within medical centers or dispatch of such psychologists from administrative bodies to medical centers","support groups led mainly by medical centers and administrative bodies","cooperation with psychology professionals","specialists' participation in and support for self-help groups","administrative bodies' financial support and consulting services for self-help groups","opportunities provided by relevant organizations to learn about grief care and to discuss difficult cases", and "information management by administrative bodies".

It is necessary to determine whether our tentative model is useful in the community.

KEY WORDS

perinatal period grief care stillbirth neonatal dath cooperation system

Introduction

Among people who have lost a loved one, long-term or chronic grief is likely to progress to a morbid state; therefore, grief care is important to prevent such grief. In the U.S. and some European countries, where grief care is advanced, the cost of this care can be covered by a public funds or by insurance[1)], while in Japan, the government does not provide financial support for such care. However, since around 2008, seminars have been held in which human resource staff are educated to become grief care advisers[2-4)], books about perinatal grief care have been published[5-6)], and training programs for perinatal loss care givers have been implemented[7)]. However, such support and programs have focused mainly on care provided during hospitalization for childbirth, and limited studies have investigated methods of regional care and the state of support for post-discharge regional cooperation.

After hospital discharge, some women are able to overcome their grief only with their families' support, but they presumably receive support from family members whose relationship with these women differ among them, while adjusting to their environment.

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Therefore, it is necessary to establish a support system that facilitates individualized cooperative grief care using appropriate human and social resources, and a system that allows those in grief to choose support according to the type of cooperation available between medical centers and the community. The present study aimed to: 1) clarify the current state of and issues regarding post-discharge perinatal grief care and regional cooperation by conducting a national survey involving medical centers, administrative bodies, and self-help groups, and 2) design a tentative regional cooperation system that facilitates the provision of support according to the needs of care receivers in cooperation with supporters.

By developing and implementing such a cooperation system, it may be possible to provide grief care not only in medical centers, but also in the community and, thus, support women suffering from loneliness and grief in the community.

The perinatal grief care described in this study refers to 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 separating from their children, and for overcoming their grief.

The present study aimed to: 1) clarify the current state of and issues regarding post-discharge perinatal care and regional cooperation in medical centers (obstetrical departments, MFICU, and NICU) and the community, such as health centers, municipal centers, and self-help groups including support groups (hereafter referred to as self-help groups), and 2) design a tentative regional cooperation system model for perinatal grief care based on the investigation described in 1).

Methods

[Purpose 1]

1. Survey period and subjects of survey

The study period was between October 2012 and May 2013. Concerning medical centers, the authors investigated 314 obstetrical departments and MFICUs (hereafter referred to as obstetrical departments), and 314 NICUs in general perinatal medical centers and regional perinatal medical centers throughout Japan. Concerning administrative bodies, the authors investigated 393 health centers and 494 municipal centers (designated cities, core cities, special cities, and special wards) throughout Japan. In addition, the authors investigated 25 self-help groups throughout Japan comprised of women who had lost a child, and these women's' families. In these medical centers and administrative bodies, the questionnaire was completed by staff members providing perinatal grief care as their main duty or those in managerial positions. In the self-help groups, the questionnaire was completed by representative staff members.

2. Survey methods

Our investigation was conducted using an anonymous self-completed questionnaire. Before developing this questionnaire, the authors interviewed a few health centers in one prefecture and two municipal staff members in charge of mother-child health to better reflect their topics of concern brought in the question items regarding administrative bodies.

3. Content of the survey

The authors investigated the backgrounds of the organizations studied (e.g., annual number of deliveries, numbers of stillbirths and neonatal deaths, number of staff members, timing of self-help group, and activities of these organizations), hospitalization care provided at the time of stillbirth or neonatal death, state of such care, post-discharge support, state of and issues regarding cooperation with other professionals, organizations, and self-help groups, as well as relevant proposals.

4. Analysis method

Descriptive and qualitative content analyses were performed.

5. Ethical considerations

It was explained that withdrawal from the study was possible, non-participation in the study would not cause any demerits, the identity of the studied organizations would not be disclosed, and appropriate actions would be taken for those experiencing altered feelings during the investigation (for self-help groups only). A response to the questionnaire was interpreted as having consented to participate in the study (the self-help groups were also requested to fill out an agreement document for study participation). This study was subsidized by a 2011-2013 FY Grant-in-Aid for Scientific Research, and was conducted with the approval of the medical ethics committee of Kanazawa University (No.406).

[Purpose 2]

On the basis of the investigation described in Purpose 1, the authors designed a diagram showing the current state

of and issues regarding post-discharge perinatal grief care and regional cooperation. After organizing this diagram, the authors designed a tentative regional cooperation system model for perinatal grief care. The authors then presented this model to 5 professionals with expertise in maternal nursing and midwifery, and revised it based on their opinions.

Results

1. Current state of and issues regarding post-discharge perinatal grief care and regional cooperation in medical centers, administrative bodies, and self-help groups

1) Health care institutions

Responses were returned from 136 obstetrics departments (recovery rate: 43.3%), and 119 NICUs (recovery rate: 37.9%).

(1) Characteristics of centers surveyed

The annual numbers of deliveries, stillbirths, and neonatal deaths for the obstetrics departments and NICUs are shown in Table 1. The mean numbers of nurses were 32.8 ± 18.0 and 35.1 ± 4.5 for the obstetrics departments and NICUs, respectively.

(2) Perinatal grief care after hospital discharge

The main form of support provided by the obstetrics departments after discharge was "face-to-face counseling at 1-month health checkup" (45.6%), while NICUs mainly used "paper-based communication (letter/e-mail)" (27.8%), "calls and visits" (24.3%) (Figure 1).

(3) Post-discharge collaboration with other professionals

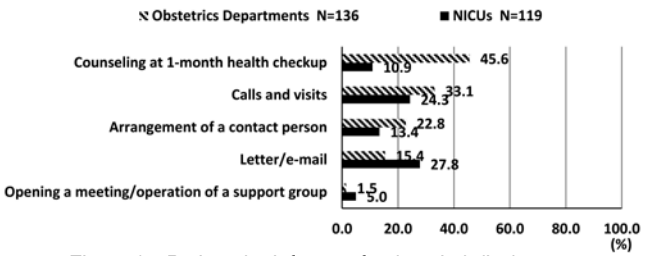
Regarding collaborative partners that provide grief care services after discharge, "public health nurses" was cited most frequently, followed by "obstetrics departments" (72.1%), and then "NICUs" (51.3%). There was little collaboration with "self-help groups", which were merely mentioned in leaflets (Figure 2).Other partners included an in-hospital caseworker, a social worker, a chaplain, the outpatient department, and a liaison nurse.

(4) Issues regarding post-discharge perinatal grief care (Figure 3)

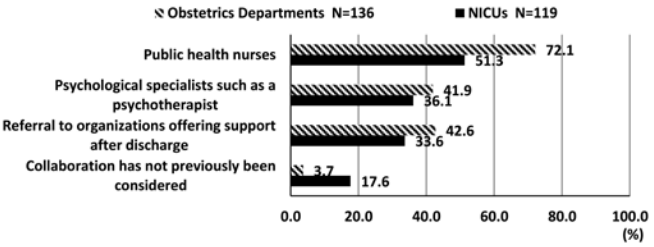
Issues regarding post-discharge care included "insufficient manpower (caregiver shortages and a lack of skills to provide care)", and "insufficient post-discharge care systems (checkups available for a period of up to 1 month after discharge)". Issues regarding regional

Table 1 Characteristics of Health care institutions

	Obstetrics Departments N=136		NICUs N=119	
	n	%	n	%
The annual numbers of deliveries				
～99	1	0.7	0	0
100～299	12	8.8	14	11.8
300～499	35	25.7	27	22.7
500～799	51	37.5	43	36.1
800～999	20	14.7	6	5.0
1000～	17	12.5	28	23.5
Unanswered			1	0.8
The annual numbers of stillbirths				
～2	32	23.5		
3～7	28	20.6		
8～9	19	14.0		
10～14	17	12.5		
15～19	10	7.4		
20～	20	14.7		
Unanswered	10	7.4		
The annual numbers of neonatal death				
～2	98	72.1	59	49.6
3～7	17	12.5	40	33.6
8～9	7	5.1	8	6.7
10～14	2	1.5	7	5.9
15～19	2	1.5	1	0.8
20～	10	7.4	0	0
Unanswered			4	3.4



Figuer 1 Perinatal grief care after hospital discharge



Figuer 2 Post-discharge collaboration with other professionals

cooperation included "insufficient information about collaborative partners", an "insufficient number of self-help groups to which grieving women can be referred", "gap in knowledge and awareness among staff members in charge", and "lack of systems facilitating the sharing and management of information".

2) Administrative bodies

Responses were returned from 184 health centers (recovery rate: 46.8%), and 71 municipal health centers (municipal centers) (recovery rate: 14.4%).

(1) Characteristics of centers surveyed

The annual numbers of stillbirths and neonatal deaths for the health and municipal centers are shown in Table 2.The mean numbers of persons in charge of maternal and child health were 2.5 ± 1.6 and 11.5 ± 11.4 for the health and municipal centers, respectively.

(2) State of perinatal grief care in administrative bodies

Of the responding centers, 38 health centers (20.7%) and 23 municipal centers (32.4%) provided grief care services, and of those, 9 health centers (23.7%) and 4 municipal centers (17.4%) answered that systems for such care had been virtually developed and implemented.

The annual numbers of cases in which grief care was provided were 0 to 3 in 70% of both the health and municipal centers. More common factors conducive to the initiation of grief care were "procedures for medical and infant care services" for the health centers (78.9%), and "request from medical institutions" for the municipal centers (65.2%) (Figure 4).

Regarding visits, half of the health centers implemented the visit together with municipal public health nurses, whereas half of the municipal centers did so by pairing with experienced staff. It took 30 minutes to 2 hours to

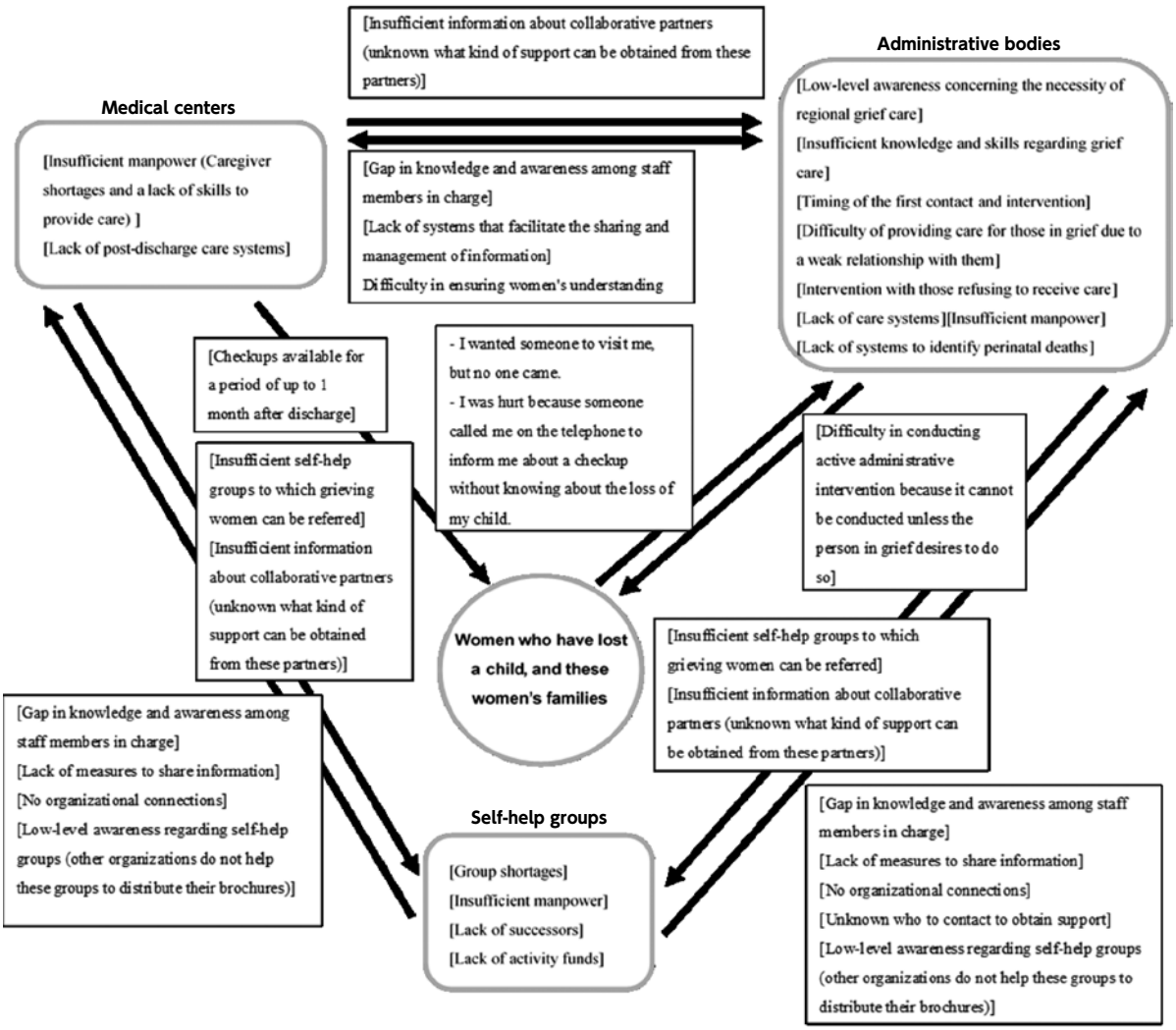


Figure 3. Issues regarding post-discharge perinatal grief care and regional cooperation

provide grief care per a visit in 80% of both the health and municipal centers, with the frequency of visits and duration varying among the cases (1 to 10 or above and up to 5 years, respectively). Eighty percent of both the health and municipal centers answered that care sharing was based on "consultation with a chief or other staff", whereas 20 to 30% answered that it was based on "case conference". For learning about grief care, 30% answered "personal learning" and half of the centers answered "no learning".

The most common reason why the centers had not previously provided grief care was that "they had not previously received a request for collaboration" (70%). Other reasons included "no way to identify stillbirths/ neonatal deaths".

(3) Interprofessional cooperation obtained by administrative bodies

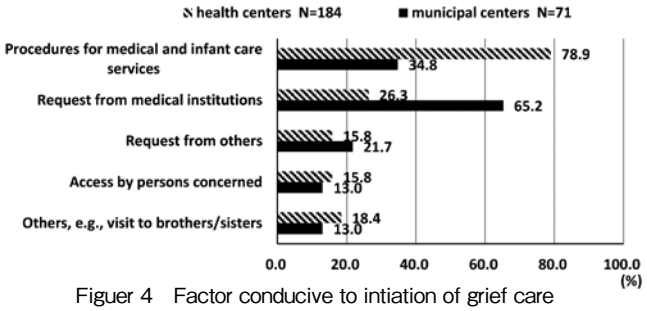
The most common answer provided by the health centers was "collaboration with municipal centers" (27.2%), whereas that of the municipal centers was "collaboration with psychological specialists" (28.2%). Very few health and municipal centers answered "direct collaboration with self-help groups", and 10 to 20% of the centers answered "collaboration not previously considered" (Figure 5).

(4) Issues regarding perinatal grief care in administrative bodies (Figure 3)

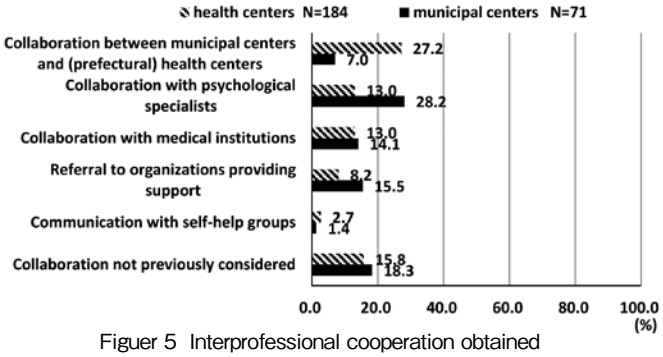
The issues regarding perinatal grief care in administrative bodies included "low-level awareness concerning the necessity of regional grief care", a "lack of knowledge and skills regarding grief care (timing of the first contact and intervention with those in grief, difficulty of providing care for those in grief due to a weak relationship with them, and intervention with those refusing to receive care)", "lack of care systems", "insufficient manpower", "lack of systems to identify perinatal deaths due to stillbirth or neonatal death", and "difficulty in conducting active intervention because it cannot be conducted unless the person in grief desires to do so". The issues regarding regional cooperation included a "gap in knowledge and awareness among staff members in charge" and "lack of systems that facilitate the sharing and management of information (difficulty in ensuring grieving women's understanding)".

Table 2 Characteristics of administrative bodies

	healthcenters N=136		municipal health centers N=119	
	n	%	n	%
The annual numbers of stillbirths				
1～4	9	4.9	10	14.1
5～9	21	11.4	4	5.6
10～19	35	19.0	10	14.1
20～29	32	17.4	3	4.2
30～39	27	14.7	8	11.3
40～49	15	8.2	6	8.5
50～	43	23.4	6	8.5
Unanswered	2	1.1	24	33.8
The annual numbers of neonatal death				
1～2	126	68.5	28	39.4
3～4	32	17.4	13	18.3
5～7	14	7.6	8	11.3
8～9	3	1.6	2	2.8
10～	3	1.6	1	1.4
Unanswered	6	3.3	19	26.8



Figuer 4 Factor conducive to intiation of grief care



Figuer 5 Interprofessional cooperation obtained administrative bodies

3) Self-help groups

Responses were returned from 15 self-help groups (recovery rate: 60.0%)

(1) Backgrounds of the self-help groups

In large groups with their branches located throughout Japan, the number of operating staff members was high, while some small groups were run by a single person. Of the 15 self-help groups studied, more than 70% have operated for longer than 10 years, and 73.3% were employing healthcare providers (Table 3). Two of the 15 groups were support groups operating with healthcare providers.

(2) State of activities of self-help groups

All groups had discussions as an activity (Figure 6). These discussions were held once per 2 to 3 months in groups with many staff members, but were irregularly held or currently suspended in groups with a small number of staff members (Table 4). The activity funds of these groups were mostly covered by donations, as they tried to minimize the burden on group members. The fee for participating in a group discussion was less than 1,000 yen in all groups. An annual membership fee system was employed by groups whose branches were located throughout Japan. On the other hand, some groups raised their funds by selling books/brochures, collecting money from group members, or opening a flea market. The annual number of inquiries received differed according to the group's size and skills for public relations. However, in all groups, inquiries were made most commonly by those with experience of grieving at the loss of a child (86.7%), with few inquiries made through medical centers and administrative bodies (26.7 and 13.3%, respectively).

(3) Cooperation between self-help groups and professionals/specialized agencies

Among the self-help groups studied, 46.7 and 26.7% received cooperation or support from medical centers and administrative bodies, respectively (Figure 7). This cooperation was provided mainly by distributing self-help groups' brochures in these centers or bodies. Thus, such cooperation was based on the idea of supporting individuals rather than establishing organizational connections. One administrative body provided a venue at a regular time in which self-help group members gave consultations to outsiders.

(4) Issues regarding self-help groups' activities and cooperation (Figure 3)

The issues regarding self-help groups' activities included an "insufficient number of self-help groups", "lack of

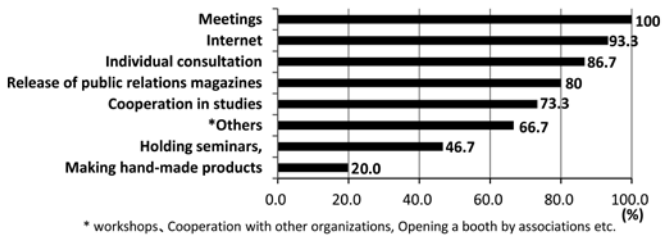
Table 3 Characteristics of self-help groups N=15

Number of operating staff members			Number of years since group establishment			Percentage of healthcare providers *		
	n	%		n	%		n	%
1	3	20.0	~4	3	20.0	0.0	4	27.0
2~4	2	13.0	5~9	1	7.0	0.1~9.9	2	7.0
5~9	3	20.0	10~14	6	40.0	10.0~24.9	3	20.0
10~19	6	40.0	15~19	2	13.0	25.0~49.9	4	40.0
20~	1	7.0	20~	3	20.0	50.0~	2	13.0

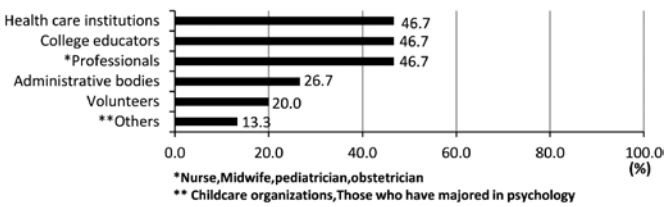
* Including healthcare providers with experience losing a child

Table 4 State of discussions held by self-help groups N=15

Frequency of discussions			Number of those participating in discussions		
	n	%		n	%
Every month	1	6.0	0~ 4	3	20.0
Every 2 or 3 months	8	53.0	5~ 9	7	47.0
Every 4 months	1	7.0	10~14	3	20.0
Once or twice a year	3	20.0	15~	2	13.0
Irregular	1	7.0			
Suspended	1	7.0			



Figuer 6 State of activities of self-help groups n=15



Figuer 7 Cooperation between self-help groups and professionals/ specializedagencies n=15

manpower (heavy burden for representatives)", "successor shortages", and "insufficient activity funds". The issues regarding cooperation included a "gap in knowledge and awareness among staff members in charge", "poor organizational connections", "lack of measures to share information", and "low-level awareness regarding self-help groups".

2. Designing a tentative regional cooperation system model for perinatal grief care

On the basis of the investigation described in Purpose 1, we designed a tentative regional cooperation system model for perinatal grief care. We then asked professionals with expertise in maternal nursing and midwifery for their opinions about this model, and made the necessary revisions (Figure 8).

This cooperation model included "assignment of those in charge of post-discharge grief care in medical centers", "development of a system to report pediatric deaths from medical centers to administrative bodies", "assignment of clinical psychologists within medical centers or dispatch of such psychologists from administrative bodies to medical centers", "support groups led mainly by medical centers and administrative bodies", "cooperation with psychology professionals", "specialists' participation in and support for self-help groups", "administrative bodies' financial support and consulting services for self-help groups", "opportunities provided by relevant organizations to learn about grief care and to discuss difficult cases", and "information management by administrative bodies".

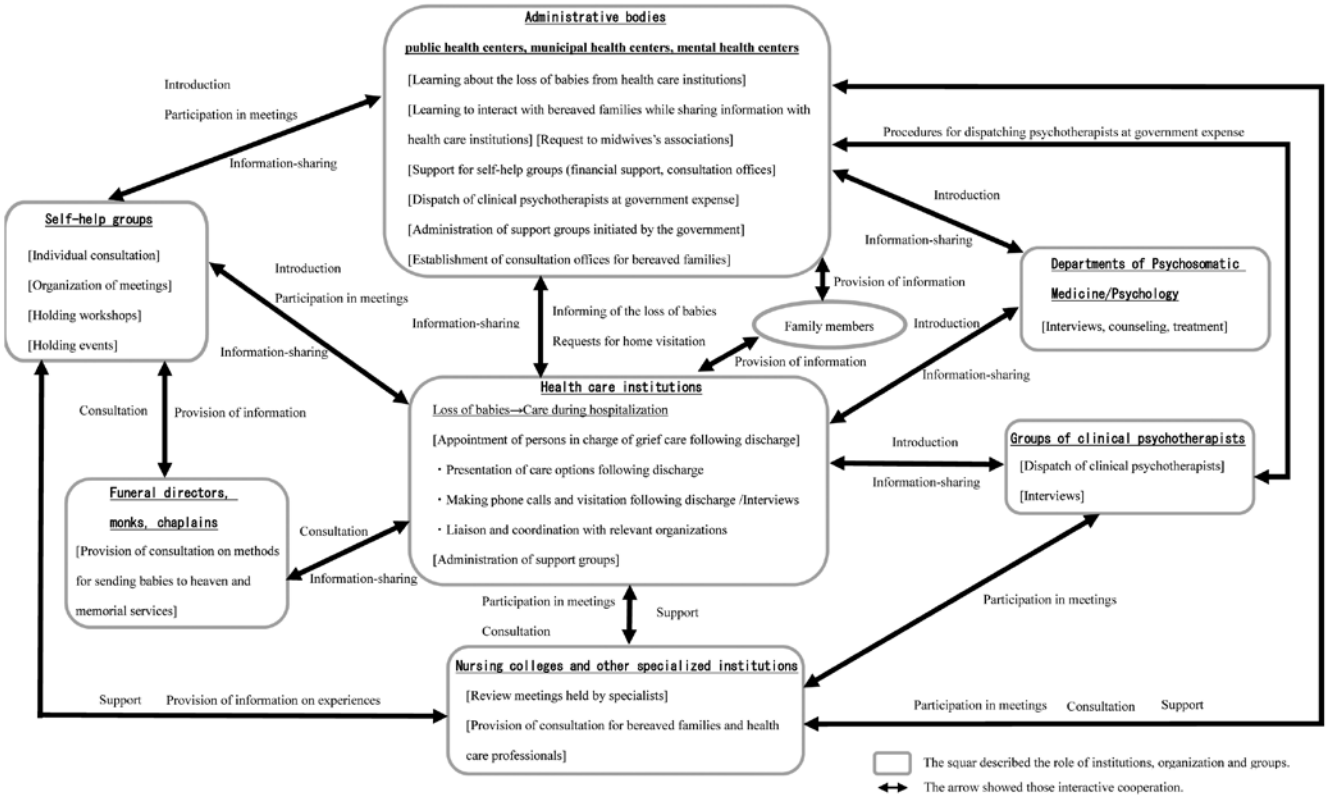


Figure 8. Tentative design of a regional cooperation system model for perinatal grief care

Discussion

1. Discussion of cooperation systems based on the current state of and issues regarding post-discharge perinatal grief care

Among the medical centers studied, the extent of providing post-discharge grief care was generally lower than that of providing grief care during hospitalization. Previous studies[8-11] also reported insufficient post-discharge grief care; however, the extent of providing post-discharge grief care in obstetrical departments is increasing. In NICUs, it is difficult to intervene with patients after discharge, as they do not usually undergo checkups afterward, and only 20 to 30% of the NICUs keep contact with patients after discharge by means of telephone, letters, or e-mails. Concerning post-discharge cooperation, 72.1 and 51.3% of the investigated obstetrical departments and NICUs cooperated with public health nurses, suggesting promoted awareness among these departments and units regarding post-discharge regional cooperation. To further promote this cooperation, it is necessary to assign those who are able to intervene with post-discharge patients continuously, and establish a system to provide both individual and organizational support for these patients. However, it is difficult to provide sufficient support for such individuals only in medical centers in terms of manpower. If medical centers present available post-discharge care options to grieving women and their families, and make adjustments with relevant organizations, these individuals may be able to receive the necessary support more effectively. To propose these options, various professionals need to have thorough discussions regarding available interventions.

Administrative bodies had low-level awareness regarding grief care provided for those who have lost a child due to stillbirth or neonatal death. In addition, 20 to 30% of the investigated bodies provided such care, and few bodies had an appropriate care system. This suggests that administrative bodies are lacking in providing grief care and, thus, it is necessary to promote their awareness regarding such care. In particular, a major issue identified was that these bodies do not have a system to identify perinatal deaths. Because municipal health nurses are usually not allowed to affiliate with officials in charge of family registration from the perspective of protecting personal information, especially in cases of stillbirth, these nurses usually have no means for identifying pediatric deaths. In some cases, nurses contacted families suffering from a stillbirth without knowing it, and caused emotional discomfort. To prevent such cases, it is necessary to promptly establish a system that facilitates reporting of all pediatric deaths from medical centers. In addition to providing grief support, it is also imperative to take measures to prevent secondary damage. According to our investigation, 50 to 70% of the medical centers cooperated with public health nurses, but only approximately 20% of the administrative bodies cooperated with public health nurses. The low rate of collecting completed questionnaires from municipalities may have partially contributed to these results, but a gap in cooperation may also exist between medical centers and administrative bodies. Therefore, it is necessary to deliberate the ways in which different types of organizations can cooperate with each other according to the needs of grieving women and their families.

Self-help groups reported many challenges in maintaining their activities in terms of both manpower and financial requirements. Therefore, these groups need to establish an organizational system that facilitates support of group operations. This support includes opportunities provided by medical centers and administrative bodies for those who have lost a child to gather, human resource support for group operations, and activity funds donated by administrative bodies. In addition, cooperation with administrative bodies may not be maintained if staff members in charge change; hence, it is necessary to ensure continued cooperation by adopting organizational approaches. In the U.S. and Europe, regional grief care is supported by a large amount of financial contribution and volunteer work, but it is difficult for Japan to employ this system. Therefore, in Japan, it is necessary to cooperate with regional self-help groups using existing systems, which is an approach unique to the country. The latest handbook on bereavement research written by Stroebe[12] reported that human and monetary costs are required in order to provide care for bereaved families. Among the measures related to mother-child health, public funds are preferentially used for the prevention of child abuse, and limited budgets are spent for grief care due to a small percentage of individuals requiring such care. However, more public funds should be used for grief care due to the possibility that an individual grieving at a loss of a child may raise their other children inappropriately[13], and that

preventing the aggravation of bereaved individuals' health may lead to the avoidance of social damage and a reduced medical expenditure[14]. Furthermore, as the number of self-help groups intended for those who have lost a child is small, some of those requiring such care live far from a self-help group, and are unable to utilize one. Therefore, for these individuals, it is necessary to obtain care online[15, 16].

Thus, the authors hope that organizations involved in grief care, mainly medical centers, administrative bodies, and self-help groups, use our models to share their roles and provide support and cooperation according to the needs of support receivers.

2. Prospects

The authors are planning to investigate relevant professionals using the Delphi method with the aim of determining the usefulness of this model and further improving the model (this investigation is currently conducted as a part of a Challenging Sprout Research under Grants-in-Aid for Scientific Research between 2014 and 2016).

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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の試案

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要　　旨

周産期に児を喪失した母親は退院後の生活の場において、孤独に陥りやすく、悲しみは深く、持続しやすい。そこで、本研究は全国の周産期母子医療センター、保健所・市区町村、自助グループを対象に退院後のグリーフケアと地域連携の現状・課題を明らかにし、周産期のグリーフケアの地域連携システムモデル試案を提示することを目的とした。計 475 か所の支援施設から自記式質問紙による有効回答を得て、記述統計解析および質的内容分析を行った。その結果､退院後の母親と家族に対するグリーフケアが十分ではない現状が明らかになった。さらに地域連携の現状･課題をもとに地域連携モデルを試案した。連携モデルの概要は【医療機関での退院後のグリーフケア担当者の設置】､【医療機関から行政への児の死亡連絡体制の整備】､【医療機関内に臨床心理士の配置】もしくは、【行政から医療機関への臨床心理士の派遣】【医療機関・行政主体でのサポートグループの運営】､【心理的専門家との連携】､【自助グループへの専門家の参加・サポート】､【行政の自助グループへの経済的支援・相談窓口の設置】､【関係機関によるグリーフケアの学習・困難事例の検討会の企画】､【行政での情報管理】等である。

構築した本試案モデルの地域での有用性を検討することが今後の課題である。