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Associated Factors of Psychological Distress among Japanese Pediatricians in Supporting the Bereaved Family Who Has Lost a Child

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ABSTRACTS

Purpose: The psychological distress of pediatricians is a major problem in bereavement care. In this study, the primary factor related to distress is clarified and the future directions of bereavement care provided by pediatricians are examined.

Method: A questionnaire was mailed to Japanese pediatricians belonging to the High-risk Infant Follow-up Association and the Society of Child Neurology. Doctors who actually experienced bereavement care were divided into high and low distress groups. We conducted a comparison of the variables for the two groups using a logistic regression analysis, and the primary factor related to psychological distress was analyzed by the odds ratio (OR) and 95% confidence intervals.

Results: The primary factors related to psychological distress were found to be the following 4 items: "gender," "years of experience," "acquisition of coping method," and "feelings of helplessness." In the high distress group, most pediatricians were women, lacked experience, had no coping methods, and felt helplessness.

Conclusion: Countermeasures are required for people feeling strong psychological distress. It is necessary to let pediatricians know that their support is helping the bereaved families and to strive to improve their feelings of helplessness. Education for appropriate coping methods and self-care is required for pediatricians desiring to study bereavement care. Consideration is particularly required for doctors who are female and those who lack experience.

INTRODUCTION

Bereavement for a valuable family member is a painful and sorrowful life-event no matter what the situation. In particular, "the death of a child" causes an extreme shock and a long-standing influence on the bereaved. Compared to other bereavements, parents who have lost their child, have been reported to have a very strong grief reaction 13)15)16), and their rate of mortality and mental illness are increasing 4)5). Furthermore, it is said that various problems arise, such as the effect on surviving siblings and disruption of the family system 15) 18). With these facts, the death of a child is one of the associated factors that raise the risk of complicated grief.

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People who care for the bereaved family following the death of a child are not necessarily health care providers. However, support by medical practitioners help to reduce guilt and isolation of the bereaved family's feelings and increase their empowerment, and they are in the best position to explain the cause of death following bereavement and to listen closely to what the bereaved family has to say 8). Furuhashi et al 4) performed interviews with bereaved families and reported that for bereaved families who had lost a child, the medical practitioners who worked with them in the terminal stage and the moment of death could easily "listen to our feelings", and the families could easily express their thoughts openly.

However, on the other hand, with the survey we conducted on Japanese pediatricians 20), there were many pediatricians who had feelings of "psychological pain", "exhaustion" and a state of high distress when providing support for bereaved families. The psychological distress of doctors during bereavement care is a serious problem.

Accordingly, in this study we focused on the distress of Japanese pediatricians who have actually supported bereaved families; we investigated the associated factors related to the distress; and we discuss the future direction for supporting bereaved families through the problems in the current situation of pediatricians.

METHODS

We obtained an informed consent from each respondent with the returned questionnaire. The study design and procedure were reviewed and approved by the Research Ethics Committee of Konan Women's University. We asked consent and cooperation from the High Risk Infant Follow-Up Association, as well as the Japanese Society of Child Neurology, and a survey was mailed to Japanese pediatricians belonging to each group. On the basis of ethical consideration, the following two items were specified on the survey forms: that it was anonymous and individual respondents would not be specified, and that consent for decision to cooperate with the research would be obtained by returning the survey.

The subjects were 312 pediatricians of the High-Risk Infant Follow-up Association. The questionnaires were sent between February and March of 2011. For the Japanese Society of Child Neurology, we sent questionnaires to the 66 committee members of the Public Relations Committee between October and December of 2011, and we requested that they be distributed to the members of the Japan Society of Child Neurology using the 'snowball sampling'. The distribution number was 242 in total.

The questionnaire consisted of items on demographic characteristics such as gender, age, number of years of experience as a pediatrician, etc.; then we next asked about personal experience in supporting bereaved families, official bereavement care, such as self-help groups in the hospital, sending letters, consultations, and coping methods when providing support for the bereaved family; how often they experience psychological distress; and experiences of professional education in bereavement care. Next, we asked whether they agree that pediatricians should support the bereaved family. Finally, we asked about 'levels of consciousness for bereavement care': (1) meaningfulness of bereavement care, (2) concern about bereavement care, (3) knowledge about bereavement care, (4) skills for bereavement care, (5) information about bereavement support, such as self-help groups, (6) anxiety about hurting the bereaved family, (7) avoiding a child’s death and bereavement, if possible, (8) feelings of helplessness in bereavement care, (9) increase of fatigue during bereavement care, (10) desire to study bereavement care, and (11) necessity for cooperation with professionals. The levels of consciousness were measured with a 5-point response scale (from “strongly agree”=1 to “strongly disagree”=5).

For the first analysis, all descriptions of the responders were measured. After confirming that there was no large difference in the trend of the answers between the two groups, the data was combined. Next, the data from the subjects who had actually experienced supporting a bereaved family was analyzed using the SPSS version 19.0 of the Windows statistical package.

We divided the subjects into two groups based on the level of psychological distress. The subjects that stated they 'always' or 'often' felt pain during bereavement care were classified as the " High Distress Group". The subjects that stated they "sometimes', 'rarely', or 'never' felt pain during bereavement care were classified as the "Low Distress Group". The prevalence of bereavement care distress was compared between the two groups on the basis of their demographic variables (χ^2 test).

For each item of the levels of consciousness for bereavement care, "strongly agree" and "agree" are represented as a "Yes" answer. "Neither agree or disagree", "disagree", and "strongly disagree" are represented as a "No" answer. A χ^2 test was carried out between the two groups on the basis of the "Yes" and "No" of the level of consciousness for bereavement care.

In addition, we conducted a comparison of the variables for high and low distress groups using a logistic regression analysis after the significant level for variable selection was set at 0.20 ($\chi 2$ test); the items included were gender, years of experiences as a paediatrician, coping methods, concern about bereavement care, feelings of helplessness in bereavement care, increase of fatigue during bereavement care, desire to study bereavement care and necessity for cooperation with other professionals. The primary factor related to psychological distress was analyzed in terms of odds ratio (OR) and 95% confidence intervals.

RESULTS

1. Respondents

We received responses from 130 people of the High-Risk Follow-Up Association, and 109 people of the Japanese Society of Child Neurology, making a total of 239 responses (response rate was 42.3% and 45.0%, respectively). Of the 239 responses, there were 193 people (80.8%) who stated that they had performed bereavement care, so the analysis targets were then considered to be 175, excluding the data of 2 or more missing values.

The 175 respondents included 107 males (61.1%) and 68 females (38.9%). The average year of experience as a pediatrician was 22.6 years. Also, the number of losses of children during the past year was an average of 2.56.

The type of support for the bereaved families by the 175 pediatricians is shown in Figure1. Almost half of the pediatricians had actually attended funeral services, consulted by telephone and/or consulted directly.

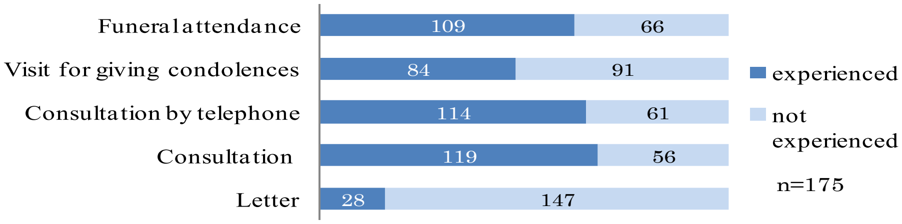

Figure 1.　Type of support by pediatricians who have experienced bereavement care

Table I. Description of respondents and prevalence of bereavement care distress

			High Distress		Low Distress		p-value
	n	%	n	%	n	%	
Sex*							
Male	97	55.4	52	29.7	55	31.4	**0.029**
Female	78	44.6	45	25.7	23	13.1	
Years of experience as a pediatrician*							
<14y	47	26.9	30	17.1	17	9.7	**0.023**
15〜22y	43	24.6	29	16.6	14	8	
23〜29y	49	28.0	27	15.4	22	12.6	
>30y	36	20.5	11	6.3	25	14.3	
Official bereavement care、(ex.: self-help group)							
Available	42	24.1	24	13.8	18	10.3	0.860
Not available	132	75.4	73	42	59	33.9	
Loss of patient during past year							
Yes	97	57.0	57	33.5	40	23.5	0.436
No	73	43.0	38	22.4	35	20.6	
Coping method**							
Have	76	43.4	30	17.1	46	26.3	**0.000**
Have not	99	56.6	67	38.3	32	18.3	
Professional advisor							
Available	52	29.7	28	16.0	24	13.7	0.868
Not available	123	70.3	69	39.4	54	30.9	
Experiences of professional education for bereavement care							
Yes	46	26.3	26	14.9	20	11.4	1.001
No	129	73.7	71	40.6	58	33.1	
Should pediatricians support bereavement care?							
Agree	77	44.2	47	27.0	30	17.2	0.455
Agree but difficult to do	80	46.0	42	24.1	38	21.8	
Disagree	17	9.8	8	4.6	9	5.2	

1) Sum of each item is different due to the number of blank answers
2) * $p < 0.05$ ** $p < 0.01$
3) Items with bold p-value numbers were analyzed with a logistic regression as the explanatory variable

2. Psychological distress indicator

In Table I, the description of the respondents and prevalence of bereavement care distress is shown for the pediatricians in each group that had high or low psychological distress during bereavement care. A significant difference is shown in the three items of gender, years of experience, and coping methods. In the high distress group, most of the pediatricians were women (p<. 05), lacked experience (p<. 05), and had no coping skills (p<. 01).

In Table II, the level of consciousness for bereavement care is shown for the high and low groups. In the high distress group, most of the pediatricians felt helplessness in bereavement care (p<. 01), increase of fatigue during bereavement care (p<. 05), and desire to study bereavement care (p<. 05).

Table II. Level of consciousness for bereavement care

			High Distress		Low Distress		p-value
	n	%	n	%	n	%	
Bereavement care is meaningful.							
Yes	165	94.3	92	52.6	73	41.2	0.722
No	10	5.7	5	2.9	5	2.9	
Concerned about bereavement care							
Yes	135	77.1	80	45.7	55	31.4	**0.061**
No	40	22.9	17	9.7	23	13.1	
Lack of knowledge about bereavement care							
Yes	135	77.1	73	41.7	62	35.4	0.466
No	40	22.9	24	17.8	16	9.1	
Lack of skills for bereavement care							
Yes	121	69.1	67	38.3	54	30.9	0.508
No	54	30.9	30	17.1	24	13.8	
Lack of information about bereavement support (self-help group etc.)							
Yes	144	82.3	77	44.0	67	38.3	0.982
No	31	17.7	20	11.4	11	6.3	
Anxiety about hurting the bereaved family							
Yes	96	54.9	51	29.1	45	25.7	0.262
No	79	45.1	46	26.2	33	18.9	
Avoiding child’s death and bereavement if possible							
Yes	48	27.4	28	16.0	20	11.4	0.499
No	127	72.6	69	39.4	58	33.1	
Feelings of helplessness in bereavement care**							
Yes	70	40.2	49	28.2	21	12.1	**0.002**
No	104	59.8	48	27.6	56	32.2	
Increase in fatigue during bereavement care*							
Yes	99	56.6	61	34.9	38	21.7	**0.050**
No	76	43.4	36	20.6	40	22.3	
Desire to study bereavement care*							
Yes	123	70.3	76	43.4	47	26.9	**0.012**
No	52	29.7	21	12.0	31	17.7	
Cooperation with other professionals is necessary							
Yes	136	77.7	80	45.7	56	32.0	**0.092**
No	39	22.3	17	9.7	22	12.6	

1) Sum of each item is different due to the number of blank answers

2) For each item, ““strongly agree ”and “agree” are represented by “Yes”. “ Neither agree or disagree” “ disagree” and “strongly agree” are represented by “No”.

3) $^{*}p<0.05$ $^{**}p<0.01$

4) Items with bold p-value numbers were analyzed with a logistic regression as the explanatory variable

3. Analysis of the associated factors of psychological distress

In the multivariable model logistic analysis (Table III), the associated factors of psychological distress included four items: gender, years of experience as a pediatrician, acquisition of coping methods, and helplessness. This model was statistically significant [$\chi 2 = 33.82$, $p < .01$], with a total 76.3% correct classification. The odds ratio was the highest in 'coping ', at 3.79; 'gender' and 'helplessness' also showed high values (more than 2).

Table III. Predictors of psychological distress from bereavement care

	Regression coefficient	p-value	Odds ratio	95%CI
sex	0.73	0.047	2.07	1.01～4.22
years of experience	0.30	0.048	1.35	1.01～1.82
coping	1.33	0.000	3.79	1.92～7.47
helplessness	0.87	0.014	2.39	1.20～4.77

DISCUSSION

In recent years, the number of reports about bereavement care by medical staff providers for grieving families who have lost a child is increasing. Keicbergs et al 7) reported that, as compared to parents who experienced “unresolved grief”, parents who stated that they had “resolved grief” after the death of their child were those that had been able to have thorough discussions with a practitioner engaged in the child’s medical care ', and they had been able to share their various problems during the one month leading up to the death of their child. Therefore, bereavement care played a large role in helping parents resolve their grief for their lost child. A survey in Japan reported that roughly half of the families experiencing the death of a child due to cancer had been more effectively supported by the doctors or nurses than family members, relatives, and colleagues who had a child with cancer2).

In our study, more than 80% (175 subjects out of a total of 239) of the pediatricians stated that they provided bereavement care after the death of a child, such as funeral attendance, visit for giving condolences, consultation, etc. Furthermore, 165 of those pediatricians stated that “bereavement care is meaningful”.

However, at the same time, 40-60% of the pediatricians who had actually provided bereavement care for the families stated that “I have anxiety about hurting the bereaved family”, “I feel helpless when giving bereavement care”, and “my fatigue increases during bereavement care”. It is said that these kinds of negative emotional experiences can cause a decline in self-efficacy as a health care provider and an increase in the risk of burnout. Therefore, individual or official counter-measures are necessary14).

In this study, the associated factors were analyzed focusing on psychological distress. Our findings suggested that being female, not having coping skills, insufficient years of experience as a pediatrician, feelings of helplessness, increased fatigue, inadequate study of bereavement care, and lack of cooperation with other professionals tended to relate to high distress during bereavement care by pediatricians.

In regards to the gender differences, the results may reflect that women tend to express their emotions more than man. On the other hand, the survey done for Japanese pediatricians on job stress and ratio of leaving employment reported no gender differences 5)6)21). Therefore, female pediatricians are more affected by a child’s death.

Furthermore, the associated factor in which the odds ratio rose the highest was the lack of coping methods during painful times. Having coping methods such as “talking with a colleague, friend or family member” or “refreshing oneself” had an extremely large influence on psychological distress during bereavement care. Having these kinds of coping methods is regarded as important for the self-care of those who provide support 6). But in this study the number of pediatricians who had these kinds of coping methods was only 76 (43.3%), less than half of the total. According to prior research [1] on the stress of nurses who took part in the terminal care of dying patients, 67% had coping methods, such as talking to colleagues. Compared to these results, the percentage of pediatricians who had coping methods in this study was extremely low. In a different survey of nurses [17], coping with "having alone time" and "choosing not to think" led to difficulties in improving their feelings, and it was shown that distress tended to remain for people who did not have proactive coping methods. Also in this study, more than half of the pediatricians responded with "have no coping methods" and "there is no help for it", and the distress of the pediatricians was stronger for those who responded as such. That is, having personal coping methods for stress reduction is very important.

We found that many pediatricians have provided support for bereaved families. In the future, we should conduct better bereavement care with an understanding of the occupational distress of pediatricians. For example, pediatricians also have high distress from their professional experiences with sick children, and it is known that they have a heavier burden than other specialists. It is said that pediatricians whose office hours are very long have high distress and a low sense of self-control over their work [21]. In particular, when there is a child in the terminal stage, their work is most irregular, and a great deal of time is put into overtime. The death of a child causes more feelings of regret and grief not only for the family but also for the pediatricians. In addition, for pediatricians who must have the responsibility of the final medical treatment, the death of a child causes feelings of defeat, helplessness, and guilt, and younger doctors in particular feel more distress [12]. In this study, we found that lack of experience and helplessness were important associated factors related to psychological distress during bereavement care.

In addition, we found that despite conducting bereavement care, many pediatricians stated that they "agree but difficult to do" in response to the question "Should pediatricians support the bereaved family?" (80 subjects: 46.0 %). In spite of having a high interest in supporting the bereaved family, there are dilemmas at present of being unable to take appropriate time for that purpose. It is not realistic for busy pediatricians to carry out 'continuous' or 'frequent' support of the bereaved family. Perhaps the bereaved families themselves are not expecting support from pediatricians that is similar to a counselor. In the current Japanese medical system and framework, health care providers are not able to support bereaved families as a part of their job. In that context, it is also important in the future to create systems like those that exist abroad, where expert professionals, such as grief counselors, are involved in the support of the bereaved family [22].

Meanwhile, the speech and manner of the doctor just once during terminal care, or at the time the bereaved visits to the hospital after the death of a child, may help in the recovery of the family, but conversely it may cause such damage that they are unable to recover.

Taking this into consideration, it is thought that the following two considerations are important: raising the awareness that caring for the family by health care providers at the child's terminal stage is supportive even after the death of a child, and offering a child better terminal care on the basis of doctor-patient-family communication [11], as well as learning some ways to provide appropriate support at the time if there is a chance to connect with the bereaved family.

In regards to support for bereaved families, it is also important to revise the current state of support, which is now carried out by individual professionals, to construct a support system for pediatricians, and to improve the quality of bereavement care. For that reason, for pediatricians, the training and education system for bereavement care is necessary for those interested. From this research, the results showed that such training implementation is particularly necessary for pediatricians who are female and who lack experience.

If training systems are implemented in the future, to mitigate feelings of helplessness, it is first of all important to convey the fact that support by pediatricians is helpful in the psychological recovery of the bereaved family. In addition, as seen in the results in Table II, some aspects of bereavement care are especially necessary, such as knowledge, skills, information, etc.

Furthermore, a point particularly worth highlighting is emphasis on the importance of self-care and reflecting on self-feelings and coping skills. With support for the bereaved, it is difficult to take on the feelings of the family while ignoring one's own feelings. In Europe and America, self-care and self-awareness are very important in the training program 3). We believe that self-efficacy will increase by handling feelings of helplessness and fatigue through such a training program, and, as a result, the quality of bereavement care would be improved and advanced. In the long term, it is believed that the pediatrician's role and effectiveness in bereavement care should be made clear, and the support system that is beneficial for both the bereaved and the pediatricians should be established.

LIMITATIONS OF THIS STUDY

The response rate (42%-45%) of this study was considered relatively high, because usually the response rate of physician surveys is commonly low10)21). Our findings may better reflect the bereavement situation among pediatricians in Japan, but there is the possibility that our respondents had a high interest in this study, which had an influence on the results.

In addition to the above limitation, there is a problem in the selection of the subjects. Due to the obtaining of personal information and its protection, this study was carried out through cooperation with the High-Risk Infant Follow-Up Association, which specializes in newborn babies, and the Japanese Society of Child Neurology, which specializes in child neurology. These two groups were chosen, because most of the pediatricians in these groups must deal with a child's death frequently and would be able to provide substantial information for this study. However, the results from pediatricians in other specialties may not necessarily be the same. In future research, if possible, we would like to request the cooperation of pediatricians affiliated with other specialty societies and conduct a more detailed analysis regarding associated factors related to the psychological distress with a larger sample.

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