Maternal Uncertainty about Infants’ Hospitalization for Acute Childhood Illness: A Qualitative Study

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Abstract

Mothers often express intense stress and uncertainty when their children develop acute childhood illnesses and it is important for healthcare professionals to consider maternal uncertainty when providing support for mothers. This study aimed to examine maternal uncertainty about children’s hospitalization due to acute childhood illnesses. We recruited 15 Japanese mothers of children aged 1 - 12 months who had been hospitalized for the first time due to acute childhood illnesses, and conducted unstructured interviews with the participants at the time of discharge. Content analysis was used to examine uncertainty in their expression of their psychological state. Mothers’ uncertainty was classified into five categories: ambiguity about the severity of the illness, unpredictability of the course of the illness, discrepancy of the judgment with healthcare professionals, lack of information about the causes of the illness, and ambiguous appropriateness of management. The former three categories were reported as uncertainty of mothers of children with chronic diseases, while the latter two categories were particularly characteristic of mothers of children with acute childhood illnesses. It is, therefore, important to explore the causes of children’s illnesses and help mothers build confidence in their ability to manage their children’s illness before discharge.

Keywords

Acute Childhood Illness, Mothers, Pediatric Nursing, Qualitative Study, Uncertainty

1. Introduction

The first year of a child’s life involves several new experiences and uncertainties,
and mothers perceive an overwhelming responsibility for their child, leading to various kinds of stress [1]. That is, the contraction of acute illnesses in children has the greatest impact on mothers’ stress levels [2] [3]. A significant source of maternal psychological stress is uncertainty about a child’s illness [4].

Mishel defined maternal uncertainty as a cognitive situation wherein a parent is unable to accurately understand the meaning of the events related to the child’s illness due to insufficient information about those events [5]. Based on this theory, some studies have focused on parents’ uncertainty regarding a child with acute illness [6]. This review explored whether parents who waited for results of the diagnostic testing and whose children had serious symptoms had high uncertainty. Furthermore, situations such as lack of helpful information from health care providers and changes in the family system also lead to uncertainty in parents. In this review, children’s acute illnesses refer to severe illnesses, an exacerbation on chronic illness, or illnesses requiring major lifesaving treatment. In other reviews published thereafter, parents’ uncertainty was focused on situations wherein children required intensive care; children had cancer relapses; parents waited for hereditary disease screening test results; or the child had chronic pain [4] [7] [8]. Thus, no studies have focused on maternal uncertainty when a child has an acute childhood illness (ACI).

ACIs (e.g., respiratory infectious diseases and infectious gastroenteritis) have a sudden onset and acute recovery. ACIs often occur in children less than two years of age. Although most children with an ACI get better without an aftereffect, mothers who are uncertain sometimes find it difficult to assess the severity of their child’s illness [9] and tend to use medical services [10]. However, this practice is sometimes unnecessary from the standpoint of health care professionals, whereas it is common in Japan. The Fire and Disaster Management Agency in Japan [11] has reported that only 1.1% of the ambulance events for children with ACIs were serious cases. Japanese society has a significantly declining birthrate, which means that many first-time parents have little experience in contact with children and a lack of basic knowledge in childrearing [12]. Therefore, it is difficult for most parents to interpret the severity of signs of childhood illness and use medical services appropriately. This situation might also result in delayed consultation and aggravation of the illness [13] [14] [15]. This decision of help-seeking behavior influenced the perception of uncertainty [16] [17].

We hypothesize that the main causes of this problem in Japan as mentioned above might be due to the uncertainty of mothers regarding their children with ACI, and therefore, exploring mothers’ uncertainty could help decrease this problem. Therefore, the purpose of this study was to examine the uncertainty of mothers with children aged between 1 and 12 months who had an ACI for the first time.

2. Methods
2.1. Study Design

The present study used a qualitative descriptive design according to the consoli-
dated criteria for reporting qualitative research (COREQ) checklist [18] for this qualitative study, and collected data through open-ended interviews.

2.2. Participants

Purposive sampling was used to recruit Japanese mothers accompanying children with ACIs who were hospitalized at a certified pediatric emergency unit in a children’s hospital (primary care facility) in urban Japan. In this area, almost everyone receives more than a high school education. This hospital annually hospitalizes approximately 3000 children mainly due to ACIs. In general, mothers are the primary childcare provider, especially during infancy [19] [20] and most Japanese fathers tend to leave childcare to mothers and concentrate on work compared to fathers in other countries [21]; therefore, only mothers who have had enough information about their child’s condition—during both good health and illness—were included as study participants. Inclusion criteria were as follows: 1) the first hospitalization of the child, 2) the child was the first born and 3) less than one year old, and 4) an approximate one-week hospital stay. The one-week period was shorter than the average length of hospital stay for infants in Japan (9.0 days [22]) since ACIs generally have a short course [23]. ACIs include upper respiratory tract infections, childhood infectious diseases, gastroenteritis, and other febrile diseases [23]. We excluded the cases of chronic or genetic diseases. The chief nurse initially approached the mothers of children who met the inclusion criteria within three days after admission. The first author met the mothers following the chief nurse’s introduction and provided them with written information about the study. Participants agreed to participate in the study and completed an informed consent form.

2.3. Data Collection

Data were collected between November and December 2014 with open-ended interviews conducted on either the day of discharge or the day before discharge. The first author interviewed the participants alone and recorded the data from all cases in an isolated sound-proofed family visiting room outside the ward. The first author referred to the guidelines of interview method [24]. Following the explanation of the study purpose and the meaning of uncertainty, the first author asked the mother to explain her psychological state regarding her child’s illness and also asked in-depth questions about her uncertainty. When at least two consecutive participants provided no new information to add to the previous responses, we considered it as data saturation. We predicted that approximately 15 participants were needed for the sample size to achieve data saturation based on previous similar studies [25] [26].

2.4. Ethical Considerations

This study was approved by the Ethics Committee of Health Sciences, Osaka University (No. 300) and the Institutional Review Board of the research hospital (No. 21). Ethical considerations were as follows: 1) voluntary participation; 2)
privacy protected; 3) able to withdraw from the study at any time, even after providing written consent; 4) additional questions; and 5) all collected data would be anonymous and confidential.

2.5. Data Analysis

We transcribed the interviews verbatim using the arrangement function of qualitative data management software (NVivo ver. 10, QSR International, Japan). We reviewed and read the transcripts repeatedly to achieve immersion. The arranged verbatim record was divided into meaning units by coding. This coding process was conducted by the first author. We did a content analysis using these codes. Content analysis is a systematic and objective means of describing phenomena so that it was possible to distil words into fewer content-related categories [27]. Each code was sorted into subcategories, and each subcategory was integrated into the categories. These coding processes were recorded using an audit trail. We re-examined the raw data in each category to confirm whether the categories were supported by the raw data. This analysis was carried out by two authors and we discussed the validity of coding name.

In order to examine the reliability and consistency of the analysis, the two authors repeatedly confirmed the relevance and coherence of each step of the analysis until consensus was achieved [28]. The second author analyzed the data independently. In order to examine the credibility, the first author consulted the co-authors and participants about the meaning of the terms and its significance [29]. We referred to the literature for the definition of Mishel’s uncertainty [5] and discussed to confirm whether our findings adhered to the requirement for uncertainty. After analyzing the data, we sent each participant their verbatim report and a summary of their interview to determine the need for revisions. Finally, we discussed the reliability to identify a wider range of concepts in the data and agreed on the interpretation of the data.

3. Findings

Twenty-four mothers were recruited. Four of them complained about their poor psychological or physical condition at the time of recruitment and therefore, did not participate in the study. Twenty mothers agreed to participate in the study but five of them withdrew due to their poor physical condition or sudden discharge of their children. Ultimately, 15 participants participated in an interview. Their background data are shown in Table 1. The major characteristics of the participants were as follows: residing in cities (100%) and married (93.3%). The average duration of the interviews was 28.1 minutes (range 16 - 51).

Content analysis yielded five categories: 1) ambiguity about the severity of the illness, 2) unpredictability about the course of the illness, 3) discrepancy of judgement with health care professionals, 4) lack of information about preventives against the illness, and 5) ambiguous appropriateness about coping.

3.1. Ambiguity about the Severity of the Illness

This category indicated that mothers were unable to accurately assess their
child’s condition due to the child’s immature verbal communication. If a mother became aware of their child having an unusual condition, she could not assess the severity of her child’s symptoms. One mother said, “I have to say, I realized that my child suddenly showed some strange symptoms. Before visiting the hospital, I thought that my child had a touch of the flu, and I could only think about how something was wrong with my child” (Participant 4). Another mother said, “There weren’t any cues about the illness, as I would usually expect. I could not understand why my child was crying. I wondered where my child was hurting” (Participant 9).

A mother explained her difficulty in communicating the child’s condition to the medical staff and said, “Perhaps because this is my first child, I did not know how to inform the doctor about my child’s condition. My child was too young to explain his condition, so I had to explain it to the doctor, but…” (Participant 14).

### 3.2. Unpredictability about the Course of the Illness

This category indicated that mothers were unable to predict or imagine the course of their child’s illness. This uncertainty appeared especially when the actual diagnosis was more serious than expected one. Anxiety resulting from this unpredictability caused panic and crying in the mothers. Some mothers hesitated to be hospitalized with their children due to this uncertainty. A mother said, “My daughter will get a painful treatment, such as an infusion and I have a scary image of her hospitalization. I cannot imagine how to spend time at the hospital as an attendant. A doctor told me a little while ago that he did not know when my child would be discharged. I absolutely dislike my child being hospitalized” (Participant 4).

This uncertainty decreased with adequate and plausible explanations for the illness from the healthcare professionals, however, it reappeared at the time of discharge. Some mothers often care for their children at home excessively. A
mother said, “After all, I absolutely don’t want my child to be infected with the RS virus from now. I will stop meeting my friends and their children for a while because I don’t know how long the virus can be infectious” (Participant 15).

### 3.3. Discrepancy of Judgement with Health Care Professionals

This type of uncertainty appeared at mothers’ first contact with a doctor. Most mothers could not determine the appropriateness of treatment because they did not understand how the healthcare professional had derived at their judgment or therapeutic strategy from the child’s condition. In the acute phase, mothers think the treatment was not effective because their child’s condition seemed to worsen despite the ongoing treatment. A mother said, “A doctor said that my child would be well within a few days. I am not a doctor, so I do not know if it is true or not. When he was ill, my child sweated, and even if his fever temporarily abated, it soon returned. Because of this, I doubted whether my child would really be well” (Participant 6).

In the recovery phase, mothers did not feel the need to continue the current treatment because their child seemed to be better. Another mother said, “My child’s illness seemed to get better after three days of hospitalization. I told my husband that maybe our child could be discharged. But the doctor said that my child had to stay because there were still symptoms” (Participant 2).

### 3.4. Lack of Information about the Causes of the Illness

This type of uncertainty indicated that mothers could not explain why and how their child became ill, and appeared when they were calm enough to think of these things. The child had fallen ill despite their mothers’ efforts to prevent the illnesses. The mothers, therefore, considered various possible causes. A mother said, “Well, I just don’t know how my child got norovirus. My child was playing at the nursery for about one hour before he became sick. He might have fallen ill there. Or [it might have been when] I took him to the child play corner the day before, he fell ill there. My child was licking toys because he is very young. If that was the reason, honestly, I am afraid to go out with him during this winter” (Participant 7).

### 3.5. Ambiguous Appropriateness of Management

This category outlined situations in which mothers hesitated or became unsure about managing their child’s illness due to their lack of experience. Mothers did not know how to administer medication to the child or respond to the child’s behavior during treatment via an intravenous drip. A mother said, “This is the first time to give my child medicine. I have not taken my child to the hospital and have no experience of hospitalization. I really don’t know anything. Well, now there are communities on the Internet, so I am able to search for answers. But I’m not sure that the internet information is correct. I think that every parent is probably raising his or her child through trial and error. However, I was helpless” (Participant 11).
Although mothers often knew some possible management strategies, they could not choose the appropriate one. For example, they could not decide whether to call the ambulance, walk to the hospital, or observe the child’s condition at home. During hospitalization, they were unsure of whether they should call a nurse. A mother said, “When I noticed my child’s symptoms, I called the ambulance even though I was alone and unsure. The ambulance arrived, and the paramedics said that my child smiled and did not look so bad. Though they said that my child wasn’t crying, I didn’t know whether I should have called the ambulance. Should I only call when my child cries? I feared that it would be too late if my child cried and then lost consciousness” (Participant 11).

Mothers also expressed their uncertainty about the need for management strategies due to ambiguous explanations from healthcare professionals. For example, although a healthcare professional explained to a mother why bed rest, nutrition, and attention to the child’s behavior during the infusion were necessary, she did not receive specific instructions (e.g., how much milk she could give the child). She also did not know how much she should limit her child’s activities at discharge. A mother said, “After my child is discharged, I don’t know if I can take my child to the supermarket. I have to go the supermarket, but I don’t want to take my child out because I’m afraid his condition will worsen” (Participant 7).

4. Discussion

There have been comprehensive reviews that have explored the antecedents, consequences, management of the uncertainty of parents of children with severely acute illness, life threatening illness, or acute period of chronic illness [6] [7]. However, no studies have examined the perception of parents’ uncertainty when their child had an ACI. In this study, we showed the uncertainty experienced by mothers whose children were hospitalized due to an ACI. Maternal uncertainty was categorized into five categories: ambiguity about the severity of the illness, unpredictability about the course of the illness, discrepancy of judgement with health care professionals, lack of information about causes of the illness, and ambiguous appropriateness of management.

The parents’ uncertainty during a child’s chronic illness can be measured by Mishel’s PPUS [5], which includes 34 items. Items in the PPUS, such as “I don’t know what is wrong with my child” or “The seriousness of my child’s illness has been determined (reverse scoring)”, are similar to our first category “ambiguity about the severity of the illness”. Francis et al. reported that mothers required specific information to assess the severity of their child’s symptoms [13] [30]. Our findings that mothers of children with ACI may be uncertain about whether the child is serious or not, are consistent with these studies.

The categories of “unpredictability of the course of the illness” and “discrepancy of judgement with health care professionals” in the study were consistent with items in the PPUS. The former had a similar meaning as the literatures’ findings including the PPUS: trajectory uncertainty [6] [7] [31]. The uncertainty
with unpredictability varied with the pattern of child’s symptoms or the parents’ experience in caring for an ill child [5] and children with ACIs often show significant changes in symptoms [19] [23]. Moreover, the latter category involved items of “the effectiveness of the treatments are undetermined” or “the results of my child’s tests are inconsistent” in the PPUS. Mishel reviewed that health care professionals were not helpful in sharing information [6]. Another study reported that there was a discrepancy between the parents’ and health care professionals’ judgments about the child’s illness [32]. This study also discussed that the discrepancy could lead to mistrust in medical services [32]. Therefore, health care professionals should clearly explain the bases of their judgements regarding the severity of a child’s illness and the meaning of treatment. In conclusion, the first three uncertainties were similar to those of mothers who have children with chronic diseases.

The two categories, “lack of information about causes of the illness” and “ambiguous appropriateness of management”, were not included in any of the items of the PPUS, although the other papers had already found similar meanings. Regarding a similar meaning of the former category, one study reported that mothers were unable to receive information on what caused the child’s symptoms [25]. Langer et al. reported that mothers’ concern was closely linked to the cause of fever when their children had fever [33]. Ingram et al. also reported that all mothers of children who had cough referred to multiple causes before deciding on what to do [34]. Therefore, a lack of information about the causes of the illness is particularly important when we consider the uncertainty of mothers of children with ACI. Health care professionals tend to be interested in how to treat the illness during hospitalization and mothers often felt uncertainty about the lack of information about causes of the illness at the time of discharge. As a result, mothers took excess preventive measures at home; e.g., mother did not want to take her child out (participant 7). Healthcare professionals should explain possible preventive methods to avoid reoccurrence, e.g., hand hygiene and/or facemasks; however, evidence for the effectiveness of any preventive methods is limited [35] [36]. Therefore, they should also explain that excess preventive methods are not needed because it is impossible for mothers to prevent ACIs entirely and most children will suffer from ACIs again.

Mothers experienced ambiguous appropriateness of management of their child with an ACI. Previous studies have reported similar findings that mothers felt ambiguity about their appropriateness of management [34] [37]. Neill et al. also reported that parents’ uncertainty was evident in defining the illness and the legitimacy of seeking medical help [38] [39]. This decision of help-seeking behavior was affected by an informal social role. In our findings, the participant could not decide whether to call the ambulance or not. Although mothers felt the need to do something, they hesitated to take action because they felt ambiguous appropriateness about management or had low confidence in their skills. Such hesitation might be induced by a flood of information received by the mothers. Mothers can find various kinds of information through the Internet.
quickly and easily; however, this information is sometimes inconsistent and inaccurate. The website of the Japan Pediatric Society includes guidelines for parents using ambulances when children suddenly become ill and this authoritative guideline should be shared with families with children [40], but it does not explain how to manage children with ACIs. It is important for a mother with little knowledge and experience of childrearing to explain how to manage in this situation. When mothers become more confident and self-assured about management with their child’s ACI, it may lead a shorter hospital stay and more appropriate use of medical resources (e.g., use of ambulances, emergency outpatient visits), resulting in reduced medical expenses. We consider that understanding maternal uncertainty based on all five categories is useful for health care professionals who deal with mothers of children with ACI in a clinical setting.

This study had some limitations. First, the findings might be specific to Japanese mothers, who tend to be reserved [32]. Social factors may have affected our results because there were few supporters with experience of child-rearing surrounding the mothers due to the declining birthrate and widespread nuclear family situation in Japan. It is therefore necessary to additionally investigate maternal uncertainty across various cultures to standardize our results. Second, the degree of each category was not determined and may vary with individual background and the child’s condition. We need to make more accurate and individual assessments of maternal uncertainty at each stage in the course of a child’s illness. Based on our results, it may be necessary to develop a scale that measures maternal uncertainty for acute childhood illnesses to investigate the actual levels of these categories of uncertainty.

5. Conclusion

When their children had ACIs, mothers experienced uncertainty about the severity, cause and course of the illness, judgement of health care professionals, and management. Uncertainties due to “lack of information about causes of the illness” and “ambiguous appropriateness about management” were characteristic of perceptions among mothers with children who had ACIs. Uncertainty should be explored further in relation to individual background and stages of the child’s illness to ensure that mothers can be given appropriate support. Prior to discharge, it is particularly important for healthcare professionals to help mothers build confidence in childrearing while understanding these uncertainties.

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