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Examination of construct of “outcome” items evaluated by families of children with medical complexity using home-visit nursing services in Japan

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Abstract

This study aims to create “Outcome” items evaluated by families of children with medical complexity (CMC) (CF-Outcome) that are similar to the Home-visit Nursing Quality Indicators for Children (HNQIC) “Outcome” items, to examine the construct of “CF-Outcome.” This study was cross-sectional, and participants were 150 families of children with medical complexity. Based on the ten items of the HNQIC “Outcome” section, we developed ten outcome items evaluated with 5-point Likert scales, and tested the validity of the construct and internal consistency of the “CF-Outcome.” Spearman correlation coefficients were calculated to identify correlations between the “CF-Outcome” factors and five “Service user satisfaction” factors. The exploratory factor analysis yielded 8 items in 3 factors, with a Cronbach's α of 0.813. For the correlation between factors of “CF-Outcome” and “Service user satisfaction”, there was no statistically significant correlation between the second factor of “CF-Outcome” and the following three factors: “Service user satisfaction”: <24-hour support>, <Care according to change>, and <Proactive patient care>. However, there were statistically significant correlations among the other factors, from $r = .165$ ($p < .01$) to $r = .367$ ($p < .001$). The findings suggest the usefulness of the “CF-Outcome” for CMC families to evaluate the outcomes of home-visit nursing services. However, there is a need to improve the wording of items to eliminate variations in responses among raters. We need to clarify the concepts of the three factors further, and examine specific items that can measure the concepts.

Keywords: Children with medical complexity; Home-visit nursing; Quality Indicators; Outcome

1. Introduction

There are 20,180 children with medical complexity (CMC) in Japan [1], and this number is expected to increase. The number of children using home-visit nursing has tripled in the past decade [2]. Quality home-visit nursing care improves CMC health care and family daily life and potentially prevents emergency department and hospital use [3,4]. In the United States, outcome assessments based on the Outcome and Assessment Information Set (OASIS), which is an outcome measure used in Medicare and Medicaid home health care, have been mandatory since 1999, suggesting that the focus of quality assessment in the United States has shifted to “Outcomes” [5].

In Japan Home-visit Nursing Agencies (HNA) started providing services in 1992, and HNA providing home-visit nursing care became common throughout the country after the introduction of the Public Nursing Care Insurance Scheme in 2000. However, it is not common to change the frequency and time of service provision depending on the care quality and the outcomes. For this reason, studies to develop “Outcome” indicators for home-visit nursing and to improve care quality based on “Outcome” indicators have not been actively conducted even 20 years after the scheme introduction [6-8].

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Further, it is necessary to develop indicators that can work as standard guidelines for home-visit nursing quality evaluations in order to improve the service provision according to the care quality and outcomes. Using the Donabedian structure-process-outcome (SPO) model [9] as the conceptual framework, the authors developed Home-visit Nursing Quality Indicators for Children (HNQIC) to help home-visit nurses make straightforward care quality and outcome assessments. The HNQIC consists of 6 items for “Structure”, 22 for “Process”, and 7 for “Outcome” sections, and the reliability and validity were established [10].

The “Structure” section evaluates the structure of HNA to improve care quality, the “Process” evaluates the quality of home-visit nursing care, and the “Outcome” evaluates the changes in physical, psychological and social conditions of the CMC and the family users of home-visit nursing services during one year from the previous year. This “Outcome” section is not intended to evaluate the individual changes of CMC and their families, but is used for HNA managing leader nurses to rate on a 5-point scale, for example, whether they perceive that the number of users who have improved has increased, such as “Changes in the number of families who can respond to medical care problems” [10].

Shimanouchi [11] suggests the necessity for deliberating what should be interpreted as the outcome and how to evaluate the effectiveness and quality of home-visit care. At the same time, incorporating the outcomes assessed by patients into clinical practice is needed to provide patient-centered care [12]. A previous study that reviewed quality assessment of home-visit nursing in Japan reported that in many cases, the HNA evaluation and the user evaluation are often conducted separately, but integrating the evaluations by individual users leads to the evaluation of individual agencies [13]. With this background, we assumed that if it is possible for individual CMC families to evaluate “Outcome” items that are similar to the HNQIC “Outcome” items evaluated by HNA managing leader nurses, it would be possible to evaluate the quality of “Outcome” of individual users and the number of users whose “Outcome” has improved, resulting in more objective “Outcome” indicators.

This study aims to create “Outcome” items evaluated by CMC families that are similar to the HNQIC “Outcome” items, to examine the construct of “Outcome” evaluated by CMC families (“CF-Outcome”), and discuss whether it is possible for CMC families to evaluate “Outcome.” When home-visit nurses and user families evaluate “Outcome” from similar perspectives, this will be an opportunity to promote communication between the nurses and families, and sharing the evaluated outcomes of the two will be useful for appropriate care [14]. Further, if we address the direction of future-oriented support based on the characteristics of changes in “Outcome” including the growth of the child, such efforts may contribute to improving the quality of life (QOL) of CMC and families.

2. Material and Methods

2.1. Participants and Survey Methods

Study participants were families of children with medical complexity (CMC) who use home-visit nursing agencies (HNA) in Japan. To recruit participants, we selected agencies stating that their services were “for children” on the website of the Prefectural Home-visit Nursing Association, and agencies that provide services for children and adolescents under 20 years of age registered in the Nursing Care Service Information Disclosure System of the Ministry of Health, Labour and Welfare of Japan [15]. We sent return pre-paid post-cards to 2,685 managing leader nurses of HNA nationwide, requesting them to distribute questionnaires to the families of children using their services. In total we obtained cooperation from 110 HNA, and sent them survey packages enclosing a letter that detailed the study outline and ethical considerations, with questionnaires and return envelopes asking them to distribute the packages to potential participants. The return envelope was addressed directly to the researcher from the participant families. The survey period was between August to December of 2019.

2.2. Survey Items

Demographics of Families: Questions include ages and genders of CMC and family members, duration (in years) of using home-visit nursing services, number of HNA used, number of times to use the services per week, and availability of medical devices for use.

2.3. CF-Outcome

Because items for “CF-Outcome” are intended to identify the construct of “CF-Outcome”, they were created by revising ten draft items for the HNQIC “Outcome” section, which was developed by Sakagami, et al. [16] using the Donabedian structure-process-outcome (SPO) model [9]. We modified the wording for the “CF-Outcome” items so that families can assess the changes in physical, psychological and social conditions of the CMC and their families during the one year

from the previous survey year. For example, the item “Changes in the number of families who can respond to medical care problems”, which is intended to be assessed by HNA managing leader nurses was revised to “I am able to respond to medical care problems” for CMC families to assess their condition compared to the one previous year. In the assessment, families rated changes in CMC and family conditions compared to the previous year using 5-point Likert scales, “Strongly agree (5 points)” to “Strongly disagree (1 point)”.

2.4. Satisfaction of Home-Visit Nursing Service Users

“Satisfaction of home-visit nursing service users (Service user satisfaction)” is a scale used in Guidelines using the SPO model with established reliability and validity [17]. This scale is comprised of 14 items in five factors of “24-hour support,” “Service user-centered care,” “Care according to changes,” “Proactive patient care,” and “Interprofessional collaboration” for home-visit nursing services, and rates the responses on a 5-point Likert scale from “Strongly agree (5 points)” to “Strongly disagree (1 point)” for satisfaction with these services.

“Outcome” evaluates the effectiveness of care provided for CMC and their families to be able to improve the quality of home-visit nursing care, and “Process” is related to “Outcome” [18]. This study examines the construct of “CF-Outcome” by focusing on the relation between factors that comprise CF-Outcome and factors that comprise “Service user satisfaction.”

2.5. Analysis

2.5.1. Determination of Items of the “CF-Outcome”

Construct Validity: For the validity of the construct of the CF-Outcome, we performed an exploratory factor analysis on the 10 CF-Outcome items by unweighted least squares (promax rotation). The number of factors was determined based on the scree criterion and the number of factors with a contribution ratio of at least 60%. Factors were given names that could be interpreted from the items employed under conditions that they had a commonality of 0.16 or more, a factor loading of 0.35 or more, and did not exhibit high loadings on multiple factors [19]. We performed the Kaiser-Meyer-Olkin (KMO) test (≥ 0.5) and Bartlett’s sphericity test to measure the sampling adequacy, and determined the factor analysis fit at ($p < .05$).

2.5.2. Determination of Internal Consistency

Cronbach’s alpha coefficients were calculated to examine the internal validity of each factor identified by the exploratory factor analysis.

2.5.3. Correlation between “CF-Outcome” and “Service User Satisfaction”

Cronbach’s alpha coefficients for the five “Service user satisfaction” factors were calculated to examine internal validity. For the scores of “CF-Outcome” factors identified by the exploratory factor analysis, and those of five “Service user satisfaction” factors, Spearman correlation coefficients were calculated. We used SPSS Statistics Version 24.0 for the statistical analysis. The statistical significance level was set to 5%.

2.6. Ethics

In the letter requesting participation in the study, we explained that participation in and withdrawal from participation are entirely voluntary, that refusal to participate will not result in any disadvantage, that participants can discontinue the cooperation anytime even after consenting to the participation, that anonymity is assured in the publication of the study results, and that adding a check in the check box at the beginning of the questionnaire will be regarded as consent to the participation. This study was conducted with approval by the institution Review Board of the University the authors belong to.

3. Result

3.1. Respondent Characteristic

In total 167 CMC family users of 64 home-visit nursing agencies (HNA) (36.4%) responded to the request for participation. Of these 150 responses that had answered all items were determined as valid (32.7%) and were included in the analysis (Table 1).

Table 1 Characteristics of family members

Characteristic	Finding (n = 150)	
	Mean (SD)	n (%)
Respondent		
Mother		145 (96.7)
Father		4 (2.7)
Other		1 (0.7)
Age (mean)	39.83 (SD6.41)	
Age of child	6.95 (SD4.49)	
Years of using the home-visit nursing services (mean)	4.61 (SD3.32)	
Days a week of home-visit nursing use (mean)	3.71 (SD1.72)	
No. of agencies the respondents use		
1		97 (64.7)
2		49 (32.7)
3		4 (2.7)
Age of the children (mean)	6.95 (SD4.49)	
Medical device use		
Home oxygen therapy		75 (50)
Tracheostomy		87 (58)
Home mechanical ventilation		67 (44.7)
Gastrostomy		82 (54.7)

3.2. Determination of Items of the “CF-Outcome”

3.2.1. Construct Validity

Table 2 shows the results of the exploratory factor analysis. The number of factors in the exploratory factor analysis was determined to be 3 based on the number of factors where scree plot criteria and contribution rate become 60% or higher. Because three items were deleted when a factor loading was set at 0.40 or higher, we deleted two items (“Opportunities for children to go out have increased” and “Opportunities for interprofessional collaboration for my children and me have increased”) with a factor loading < 0.35, and we performed an exploratory factor analysis again. The “CF-Outcome” section was comprised of 8 items in 3 factors: <Changes in care skills of families> (three items), <Changes in family lifestyle> (two items), and <Continuing stable home lives> (three items). The cumulative contribution rate was 60.277%. For the sample validity, the KMO was 0.775, and Bartlett’s sphericity test showed $p < .001$ (approximate $\chi^2 = 265.325$, degrees of freedom = 28), showing the factor analysis validity.

3.3. Determination of Internal Consistency

Cronbach's alpha coefficients for the factors of “CF-Outcome” ranged from 0.631 to 0.719 (Table 2).

3.4. Correlation between “CF-Outcome” and “Service User Satisfaction”

Cronbach's alpha coefficients for the five factors of “Service user satisfaction” were from 0.631 to 0.908, showing internal consistency. For the correlation between factors of “CF-Outcome” and “Service user satisfaction,” there was no statistically significant correlation between the Factor 2 of “CF-Outcome” and the following three factors of “Service user satisfaction”: <24-hour support>, <Care according to change>, and <Proactive patient care>. However, there were statistically significant correlations among the other factors, from $r = .165$ ($p < .01$) to $r = .367$ ($p < .001$) (Table 3).

Table 2 Exploratory factor analysis of outcome assessed by families n= 150

Factor Contents (subordinate concept)	Factor 1	Factor 2	Factor 3	Comm-onality	Cronbach's α
Factor 1: Changes in care skills of families					0.719
I am able to respond to medical care problems.	0.972	0.009	-0.105	0.860	
I am able to evaluate and respond to the situations of the child.	0.744	-0.032	0.152	0.666	
I am able to prepare for emergencies and disasters.	0.406	0.369	-0.003	0.439	
Factor 2: Changes in family lifestyle					0.633
I found time to get away and rest.	-0.139	0.907	-0.033	0.707	
I save the time for siblings in the family.	0.147	0.522	-0.026	0.352	
Factor 3: Continuing stable home lives					0.639
Physical conditions of the child have stabilized.	-0.066	-0.010	1.040	0.999	
I feel the child grow and develop.	0.343	-0.122	0.391	0.345	
Length of the home care period of the child has increased.	0.103	0.358	0.363	0.446	
Sum of squared loadings after rotation	2.703	2.131	2.258		
Cumulative contribution rate	40.931	51.415	60.277		
Correlation matrix	Factor 1	-	0.468	0.510	
	Factor 2		-	0.395	
	Factor 3			-	

Unweighted least squares (promax rotation), Cronbach's α coefficient

Table 3 Correlation between “CF-Outcome” and “Satisfaction of home-visit nursing service users”

		Family satisfaction				
		24-hour support	Service user-centered care	Care according to change	Proactive patient care	Interprofessional collaboration
“Outcome” evaluated by CMC families	Changes in care skills of families	0.309**	0.405**	0.456**	0.269**	0.387**
	Changes in family lifestyle	0.165	0.241*	0.147	0.14	0.307**
	Continuing stable home lives	0.343**	0.259**	0.336**	0.267**	0.287*

*p < .05, **p < .01

4. Discussion

4.1. Sample Representativeness

The response rate for the present study was 32.7%, which is similar to the response rates of previous studies that surveyed CMC families in Japan [20,21], from 21.6% to 43.9%. The percentage of CMC using medical devices in the present study is around 50%. A previous study reported that the percentage of CMC using medical devices of pediatric home-visit nursing service users in Japan is 50–68% [22], and it may be surmised that the data of the present study represent the actual situation to some extent in terms of the characteristics of medical devices used by CMC.

4.2. Examination of Construct of the “CF-Outcome”

As the results of the exploratory factor analysis, we deleted two items with a factor loading < 0.35 . The commonality of “Opportunities for interprofessional collaboration for my children and me have increased” was low as 0.181, and that of “Opportunities for children to go out have increased” was 0.437. However, the factor loadings were in the same range as the other factors (0.217–0.298). Because the wording in these two items may have been unclear for families to evaluate, we deleted the two and performed an exploratory factor analysis again.

An item of the Factor 1 “I am able to prepare for emergencies and disasters.” and an item of the Factor 3 ‘Length of the home care period of the child has increased’ also exhibited high loadings on the Factor 2. When an item shows high loadings on multiple factors, the item may be deleted. However, in the present study, we left the items to examine the constructs. We need to clarify the concept of the Factor 2 further, and examine specific items that can measure the concept.

The factor loading for the item of the Factor 3, “Physical conditions of the child have stabilized,” exceeded 1. Sadojima et al. [23] stated that this is not applied to the Haywood case because the cause of factor loadings exceeding 1 is due to the promax rotation and commonality does not exceed 1. Therefore, we decided not to remove this item in the present study. However, the items in the ‘Physical conditions’ of children can be expected to be rated differently by different raters. We need to detail the ‘Physical conditions’ and the outcomes should be evaluated in more detail. As a result of the exploratory factor analyses, the cumulative contribution rate was 60.277%, suggesting sufficient explanatory power of the factor. For the fit of the factor analysis, the closer to 1 the KMO is, the higher the sample adequacy, and in the Bartlett’s Test of Sphericity, a sample is determined to fit the factor analysis if it is rejected at the 5% level [24]. These suggest that the structure of “CF-Outcome” can be considered to have some degree of fit for the factor analysis.

In examining the internal validity, De Vellis [25] reported that Cronbach's alpha coefficient of 0.6 to 0.7 is a minimally acceptable range. The “Outcome” of the present study satisfies this criterion. Further, the Cronbach's alpha coefficients were in the minimally acceptable range despite the small number of items (2 to 3 per factor), and the internal consistency is low. Especially in the Factor 2 and Factor 3, Cronbach's alpha coefficients were below 0.7. This suggests that there are variations in the responses among raters and that the items in each factor does not measure the construct in the same way. Based on the above, the following addresses and clarifies the concepts of the three factors further, and examines specific items that can measure the concepts. Further, we need to improve the wording of the items so that raters can make assessment with a uniform understanding.

4.3. Correlation between “CF-Outcome” and “Service User Satisfaction”

The Factor 1 and Factor 3 of “CF-Outcome” were items to measure care skills of families and the stabilization level of physical conditions of CMC. These were statistically significantly correlated with five factors of “Service user satisfaction,” suggesting that home-visit nursing services may have a direct impact. However, the Factor 2 was items to measure family lifestyle, and there were no statistically significant correlations with the Factor 3 of “Service user satisfaction.” This suggests that factors other than home-visit nursing services may be involved, but the Factor 2 is “Outcome” related to the stability and quality of the family life as a result of making the time the family can rest and interact with siblings. A study that reviewed outcome indicators for home-visit nursing used indicators to measure QOL as well as activities of daily living (ADL), health conditions of home-visit nursing service users, and changes in family caregiving skills [26]. Based on this, “Outcome” should be assessed by indicators that measure Changes in family lifestyle related to QOL (Factor 2), as well as Changes in care skills of families (Factor 1) and Continuing stable home lives (Factor 3).

Limitations

This study discussed the construct of “CF-Outcome” by examining the correlations between factors that constitute “CF-Outcome” and factors that constitute “Service user satisfaction.” However, as “Process” is related to “Outcome” [18], we needed to examine the correlations between the HNQIC “Process” and the “CF-Outcome.” Further studies are needed to examine the correlations between these two, and review the items of the “HNQIC “Process” to improve the items to become more informative indicators.

5. Conclusions

This study aimed to examine the construct of “CF-Outcome”, and discuss whether it would be possible for CMC families to be able to evaluate “Outcome.” The exploratory factor analysis showed that the “CF-Outcome” section is comprised of 8 items in 3 factors, and that there were statistically significant correlations between the factors of “CF-Outcome” and “Service user satisfaction.” The findings suggest that the wording of the items of “CF-Outcome” needs to be improved, but that the “CF-Outcome” can be a useful indicator for CMC families to evaluate the outcomes of home-visit nursing services. We need to clarify the concepts of the three factors further, and examine specific items that can measure the concepts. Further, the findings suggest the necessity to improve the wording of the items to eliminate variations in responses among raters.

Compliance with ethical standards

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Disclosure of conflict of interest

The authors have no conflicts of interest associated with this study.

Statement of ethical approval

This study was conducted with approval by the institution Review Board of the University the authors belong to.

Statement of informed consent

In the letter requesting participation in the study, we explained that participation in and withdrawal from participation are entirely voluntary, that refusal to participate will not result in any disadvantage, that participants can discontinue the cooperation anytime even after consenting to the participation, that anonymity is assured in the publication of the study results, and that adding a check in the check box at the beginning of the questionnaire will be regarded as consent to the participation.

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