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Original Article

Meaning and potential of interview data in depiction of life stories: interviews of three mothers caring for children with severe disabilities

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Abstract. [Purpose] This study aimed to review the meaning and potential of interview data for life story depiction. [Participants and Methods] The participants were three mothers who appeared to have positively accepted their daily lives while raising children with severe disabilities. Semi-structured interviews of these mothers were performed. By reference to Trajectory Equifinality Model, noteworthy experiences were extracted for individual cases from the complete records of the interviews. [Results] After the narration of their life stories, the mothers reached the following points: "Strange sense of satisfaction with living with this child," "Both the child and I are happy," and "The presence of this child allowed us to save our marriage." [Conclusion] When one talks about oneself, the past is arranged in a form that explains the present, omitting or ignoring past experiences that are not related to the present. In other words, the present condition is not the point that the mothers has reached through the narration of their life stories, but the life story has been created to explain the present condition. This means that the life story will continue to change with each new context. This is the conclusion of this study with regard to the meaning and potential of interview data.

Key words: Life story, Interview, Acceptance of disability

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INTRODUCTION

Past empirical studies on the psychosocial adaptations of mothers with children with severe disabilities have used interviews of the mothers^{1, 2}, questionnaires³⁻⁵ and memoires⁶. These studies were conducted based on the assumption that all the statements and responses made by the mothers about the past were facts. However, is it really possible for individuals to remember emotions identical to the painful emotions that were experienced several years ago? If such emotions are experienced repeatedly, the individual will not be able to live long.

"It is not correct that the past accumulates like solid materials in the space of memories, allowing the past to be preserved in its original form during the action of remembering. Instead, the past is continuously reorganized, interpreted in different ways, and thus changes in comparison to the present"⁷). Narrative is an action that creates meaning⁸), and humans find meaning in the past through narrative and thus reorganize the past while continuing to live. Particularly when one talks about oneself, the past is arranged in a form that explains the present, omitting or ignoring past experiences that are not related to the present⁹⁾. It is irrational to use data reorganized by narrative as a collection of factors. Such methods do not utilize the real meaning of the data.

The study was aimed at reviewing the meaning and potential of the interview data for life story depiction collected through

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interviews of 3 mothers who appeared to have accepted the disabilities in their children with a positive attitude.

PARTICIPANTS AND METHODS

Of the mothers of children with severe disabilities in the last year of the senior high school who were receiving physical therapy at the X Rehabilitation Center, three mothers judged during daily scenes of care as satisfying the Grayson's criteria¹⁰ for positive acceptance of disabilities were enrolled to this study. Initially, 4 mothers were enrolled in this study, but the child of one mother died during the course of the study. Thus, 3 mothers completed the study.

Two sessions of semi-structured interviews were held for each mother. The questions that were asked during the interview are listed in the Table 1. Because it was speculated that the processes that allowed these mothers to come to accept the disabilities in their children with a positive attitude were closely related to the changes in the physical functioning of their children, our interview was started with the question of each mother's expectation from physical therapy, her feeling about her child, her own affliction, her feeling about people around her, and the triggers for the changes in these aspects. These questions were placed separately for the pre-school period, the elementary school period, the junior high school period and the current senior high school period. Each interview was recorded using an IC recorder after the mother had consented of the recording of the interview.

The interview was conducted in a private room at the rehabilitation center or at the mother's home.

By reference to Trajectory Equifinality Model¹¹⁾ designed to depict diversity and similarity among individual lives underlying the narratives, first, noteworthy experiences and strong feelings were extracted from the complete records of the interviews with each mother and were arranged chronologically. The chronological experiences and feelings were then roughly classified into broad categories, and a label representing their meaning was attached to each class.

Then, the label "Becoming the mother of a child with severe disabilities," which was common to all 3 mothers, was placed at the top, and the labels for each mother (Cases 1, 2 and 3) were arranged in a row (if the labels were the same, the label was placed horizontally in the correct spot on the vertical axis). The diagram thus prepared was named, "Diagram of the life story with a child with severe disabilities as experienced by 3 mothers."

Ethical approval for this study was obtained from Ethics Committee of Kibi International University (Approval number: 13-04). Written informed consent was obtained from all participants before the study.

RESULTS

The mean durations of the interviews were 75 minutes for the first session and 54 minutes for the second session. Figure 1 shows a "Diagram of the life story with a child with severe disabilities as experienced by 3 mothers".

In Case 1, the processes by which the current state of mind ("Strange sense of satisfaction with living with this child") was reached were represented by the labels "hardships because of frequent awareness of my own unhappiness", "Blaming surrounding people", "Consider it to be fate", "Becoming aware of the feelings of surrounding people", "Finding a new direction in life after a state of resignation", and "Feeling thankful to surrounding people." In Case 2, the processes by which the current state of mind ("Both the child and I are happy. Attention is now paid to young mothers living with hardships") was reached were represented by the labels "Hardships because of frequent awareness of my own unhappiness", "Blaming surrounding people", "Becoming aware of the feelings of surrounding people", "Experiencing a decrease in envy after enduring hardships and finding myself different from the past", and "Feeling thankful to surrounding people." In Case 3, the processes by which the current state of mind ("The presence of this child allowed us to save our marriage. Thank you.") was reached were represented by the labels "Hardships because of frequent awareness of my own unhappiness", "How long will my current life as the mother of a child with severe disabilities continue? I want to live my own life", "Giving up and preparing myself for the worst", and "It may be difficult for me to endure any more. Pardon me."

DISCUSSION

In Case 1, hardships because of a frequent awareness of her own unhappiness initially caused the mother to blame surrounding people, but later guided the mother to become aware of the feelings of others, leading to a change in her view of life (Finding a new direction in life after a state of resignation) and eventually enabling her to reach her current state (Strange sense of satisfaction with living with this child).

In Case 2, hardships because of a frequent awareness of her own unhappiness initially caused the mother to blame surrounding people, but later guided the mother to become aware of the feelings of others, leading to a change in her view of oneself after experiencing affliction (Finding myself different from the past) and eventually enabling her to reach her current state (Both the child and I are happy. Attention is now paid to young mothers living with hardships).

Case 3 experienced hardships because of a frequent awareness of her own unhappiness, but raised her child while suppressing her own desires to lead her own life, eventually reaching her current state (The presence of this child allowed us to save our marriage. Thank you).

Table 1. Interview questions

Session 1

- · Expectations for physical therapy and factors triggering changes in expectations
- · Feelings toward child and factors triggering changes in feelings
- Afflictions experienced by mother and factors triggering changes in afflictions
- Session 2
- · Feelings toward surrounding people and factors triggering changes in feelings
- · Confirmation of answers to questions asked during Session 1

The answers to each question were collected separately for children of pre-school period, elementary school period, junior high school period, and senior high school period (at present).



Fig. 1. Diagram of the life story with a child with severe disabilities as experienced by 3 mothers.

The present for these mothers is not fixed. If an event that markedly shakes the basis of their daily life were to occur, their present would change remarkably. When one talks about oneself, the past is arranged in a form that explains the present, omitting or ignoring past experiences that are not related to the present⁹. If the present changes, the way in which the past is used to explain the present will also change. This means that the arrangement of the past can also be viewed as the present. In the present study, the term "present" is applicable not only to "Strange sense of satisfaction with living with this child", "Both the child and I are happy. Attention is now paid to young mothers living with hardships", and "The presence of this child allowed us to saved our marriage. Thank you," but also to the entirety of the array shown in Fig. 1. In other words, the present condition is not the point that the mother has reached through narration of her life story, but the life story may be created. This means that the life story will continue to change with each new context. This is the conclusion of this study with regard to the meaning and potential of interview data depicting the life stories of these mothers.

Also in the field of brain science, close attention has been paid to the multiple trace theory $(MTT)^{12}$ as a model of memory reconsolidation. According to the MTT, the hippocampus is always involved in the storage and recollection of memories, regardless of whether a given piece of information regarding an episode is new or old, and the old memory is transformed every time it is recollected^{12, 13}. In other words, the experience in a new context is incorporated into the old memory, thereby transforming the original memory¹⁴.

Conflict of interest None.

none.

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