

## **Caregivers' lived experience in trying to read slight movements in a child with severe brain injury: A phenomenological study**

### **ABSTRACT**

#### **Aims & objectives**

We explored caregivers' lived experience of reading slight movements of a child with severe brain injury.

#### **Background**

Despite increased need, the development of individual care for children with severe brain injuries has been prevented by their severe physical state and the poor reproducibility of their movements. In addition to a lack of evidence on the motor characteristics of patients with severe brain injury with multiple disabilities, their own development contributes to increasing variability in their states. Thus, caregivers are compelled to rely on their experiences, which have not been academically explored.

#### **Design**

A qualitative study based on van Manen's method of hermeneutic phenomenology.

#### **Methods**

Data were obtained through twenty-one 3-hour observation sessions and five 15 to 45-minute group interviews. We observed a child (called AK) with severe brain injury and his 61 caregivers, and conducted group interviews with 28 caregivers. We focused on caregivers' experiences of reading AK's slight movements. The data were interpreted based on van Manen's hermeneutic phenomenological approach.

#### **Results**

Four themes emerged as caregivers' experience in trying to read AK's slight movements. By considering "AK's physical state and his slight movements" and discovering "caregivers'

“sense of uncertainty” about AK’s slight movements,” caregivers could decipher “AK’s multiple slight movements.” “Sharing” was found as a necessary aspect of these other three themes of reading AK’s slight movements.

### **Conclusions**

We presented caregivers’ experiences as related to these four themes in their efforts to read the slight movements of AK. Due to AK’s slight movements with poor reproducibility, “sharing” was necessary to read AK’s slight movements, as it exposes caregivers’ lived experience to the interpretation of multiple caregivers.

### **Relevance to clinical practice**

These four themes may be useful for assessing, guiding, and promoting caregivers’ use of sharing when reading the slight movements of children with severe brain injury.

### **Summary box**

#### **What does this paper contribute to the wider global clinical community?**

This study focused on the sharing of caregivers’ lived experience, including their “sense of uncertainty,” in caring for a child with severe brain injury.

Optimizing care for patients whose will cannot be confirmed directly is challenging, not only in Japan but also worldwide. Our results strongly suggest that, to improve such care, we should consider caregivers’ lived experience alongside the objective data emphasized in medicine and nursing.

“Sharing” in the care of a child with severe brain injury relies solely on each caregiver’s level of awareness. As such, it can be easily put into practice regardless of the financial situation of the country or hospital/institution and of cultural differences.

**Key words:** care, child, brain injury, vegetative state/unresponsive wakefulness syndrome, minimally conscious state, sharing, caregivers, uncertainty, lived experience, qualitative research.

## **Caregivers' lived experience in trying to read slight movements in a child with severe brain injury: A phenomenological study**

### **INTRODUCTION**

Due to the greater survival odds brought on by medical advancements, the number of people experiencing a vegetative state/unresponsive wakefulness syndrome (VS/UWS; Laureys et al., 2010) or a minimally conscious state (MCS; Giacino, 2002) is increasing (Monti et al., 2010). According to a study conducted in 1994, the life expectancy of patients in a vegetative state after receiving brain injuries was 2–5 years (Ashwal et al., 1994); however, a study in 2000 indicated that the 8-year survival rate of such patients was as high as 63% (Strauss, Ashwal, Day, & Shavelle, 2000).

Persistent unconsciousness can be classified as coma, VS/UWS, and MCS. The most important difference between VS/UWS and MCS is whether there are 'purposeful behaviors in response to environmental stimuli, not due to reflexive activity' (Ashwal, 2004, p. 358). Overlooking purposeful behaviors is considered one of the main causes of misdiagnosis. At present, identifying purposeful behaviors can be done via objective methods such as functional magnetic resonance imaging (fMRI) and electroencephalography (EEG) (Peterson, Cruse, Naci, Weijer, & Owen, 2015). However, many of these methods are still under development, which means that identifying purposeful behaviors mostly relies on caregivers' clinical judgments. Unfortunately, children with severe brain injuries tend to experience multimorbidity, which can lead to diverse physical states, and the acuteness levels and children's own developmental stage (Bigler et al., 2013) make it difficult to distinguish which movements are purposeful and which are idiosyncratic phenomena resulting from that person's condition. Furthermore, the movements of people with such injuries tend to be ambiguous (Monti et al., 2010), slight, and have poor reproducibility, which similarly

contributes to the high rate of misdiagnosis (which has reached upwards of 40% of cases; van Erp et al., 2015; Monti et al., 2010).

To compensate for the insufficiency of objective data, which has been suggested as a cause of misdiagnosis, caregivers are required to make clinical judgments about patients with traumatic brain injuries based on their lived experience. One previous paper claimed that it is important to study the patient's illness experience and the real-life clinical encounters for different conditions and in different circumstances (Greenhalgh, Howick, Maskrey, Evidence Based Medicine Renaissance, & for the Evidence Based Medicine Renaissance, 2014; p. 3).

As caregivers' lived experience has not been academically studied despite its importance, we performed a phenomenological observation of the care for a child with severe brain injury (named AK). In particular, we focused on caregivers' experience of reading AK's slight movements. "Philosophical phenomenology makes explicit that it considers everything to be studied from the view point of consciousness (which can exist at many levels) or subjectivity (which also has levels)" (Giorgi, 2009, p.68). In the observation sessions, we collected data by applying phenomenological recognition, which is the basis of the phenomenological approach. This involves examining events/phenomena before objectivity arises in order to fully reveal caregivers' lived experience, which have not been considered enough in a clinical context due to their subjectivity. Along these lines, the first author has formulated several questions based on her experience in a child ward and her own past research (Kameda, 2003): What are the lives of the children with severe brain injuries? How do we support the lives of such children?

This study aims to interpret caregivers' experiences in reading the slight movements of a child with severe brain injury based on van Manen's hermeneutic (e.g. interpretative) phenomenological approach (1990).

## **BACKGROUND**

### **Difficulty of standardizing care for severe brain injuries due to poor objective evidence**

As noted above, medical developments have extended the life expectancy of children with VS/UWS and MCS (Ashwal et al., 1994; Monti et al., 2010). Furthermore, the diversity in the causes of brain injuries (e.g., head trauma, hypoxic encephalopathy, brain tumor, brain malformation, metabolic abnormality) and differences in children's development when they experienced these injuries can contribute to substantial variability in their statuses (Bigler et al., 2013). This has, however, made it difficult to standardize care for such individuals. In a previous systematic review, van Erp et al. (2014) reported that "prevalence figures varied from 0.2 to 6.1 VS/UWS patients per 100 000 members of the population. The publications' methodological quality differed substantially, in particular with regard to inclusion criteria and diagnosis verification. The reliability of VS/UWS prevalence figures is poor." (p.1361). This wide range of prevalence figures suggests that there are limitations in the objective evidence used for classifying VS/UWS and MCS.

### **Problems of objective evidence**

Because children with traumatic brain injury have limited ability to express their will, objective medical evidence is often the only data caregivers can rely on. However, these data often result in misdiagnosis. Raines and Brustad (2012, p.187) reported that recognizing changes in the state of children discharged from the neonatal intensive care unit (NICU) was one of the activities in which caregivers felt the least confidence. Furthermore, when relying only on objective data, misdiagnosis is difficult to avoid. In this way, objective evidence can be harmful to people whose clinical situation is serious (Greenhalgh et al., 2014). Another problem is that there are no ways of researching the experiences of children with severe brain injuries directly.

However, one study suggested that “the active involvement of patients’ proxies and staff enriched the assessment [of children with traumatic brain injuries]” (van Erp et al., 2015), p. 85.e13). Since evidence-based medicine, which “makes the ethical care of the patient’s top priority” (Greenhalgh et al., 2014, p. 4), is necessary and “broader, more imaginative research is needed” (p.5), we thought that the data from caregivers’ lived experience including the context of care, might improve accuracy in medical judgments concerning children with severe brain injury. Because many caregivers in clinical situations struggle to seek optimal care for children, despite their lower confidence, further research is needed to find ways of improving their confidence. In this study, we sought to do this by describing caregivers’ lived experience of reading the slight movements of AK, a child with traumatic brain injury.

### **Aim**

We aimed to interpret caregivers’ lived experience in reading the slight movements of a child with severe brain injury.

## **METHODS**

To explore caregivers’ lived experiences of reading the slight movements of a 10-year-old child with severe brain injury (hereafter “AK”), we used van Manen’s hermeneutic (e.g. interpretative) phenomenological approach (1990). This consists of observation sessions and group interviews. Because we were examining caregivers’ lived experience, such as the ‘sense of uncertainty,’ and had no way to confirm the child’s own will and thoughts, phenomenological recognition was needed to obtain the data. “Phenomenology stands for a kind of rebellion against the trend in modern science which begins with simplifying abstractions and ends with a minimum vocabulary of scientific concepts” (Spiegelberg, 1982,

p.681). More specifically, it aims to examine phenomena before consideration of their objectivity. Through such phenomenological recognition, which is the basis of the phenomenological approach, this study collected data that had not been previously considered due to their subjectivity in medical situations. These data included what the principal investigator (PI) heard, saw, smelled, touched, sensed, and thought while at AK's side. We collected as much as possible in order to compensate for AK's limited physical ability. As supplemental data, the PI wrote field notes of her experiences at AK's side during the observation sessions, which were considered interpretations of the sessions. All caregivers involved in AK's care (and daily life) during the observation sessions had to be included in the data in order to fully understand the daily care for AK. The total number was 61, which were observed by the PI in 21 observation sessions. The field notes and transcribed interviews were interpreted based on van Manen's hermeneutic (e.g. interpretative) phenomenological approach (1990).

### **Caregiver participation and setting**

Data were collected in a ward in an institution for people with severe multiple disabilities, which also had an attached special needs school. These institutions in Japan offer medical care, welfare, and education to people with severe multiple disabilities, and are based on the philosophy of "guaranteeing the right of development to all"—even those with severe multiple disabilities (Itoga, 2002). A previous study has detailed the care practices for patients with multiple disabilities by the staff of these institutions, which are based on medical and child welfare laws in Japan (Matsubasa, Kimura, Shinohara, & Endo, 2015).

Sixty-one participants were observed by the primary investigator in the observation sessions and written about in the field notes, 28 caregivers joined the group interviews, and 9 were included in our descriptions in this paper. Forty participants took part in only the



observation sessions, 9 took part in only the group interviews, and 21 took part in both; in total, there were 70 unique individuals. None of them dropped out (Table 2). Although “typical sample sizes for phenomenological studies range from 1 to 10 persons” (Starks & Trinidad, 2007, p. 1375), “the exact number of individuals needed ... depends on the goals and purpose of the study” (p. 1374). In seven explanatory meetings, all caregivers who interacted with AK were asked to participate in the study as we wanted to collect as much phenomena as possible to compensate for AK’s limited physical ability. Therefore, all caregivers who were involved in AK’s care during the observation sessions were included as participants.

### **Case description**

AK was introduced to the researchers as the child with the most severe brain injury in the institute. Caregivers initially expressed difficulty in providing care for him because of his limited physical ability. AK is a 10-year-old boy with severe brain injury due to cardiopulmonary arrest for 40 minutes when he was four months old. He could only move his neck, eyes, and mouth, and only to a very slight degree (see Table 1). For example, although he could close his eyes when it was time to sleep, the movement range of his eyelids when blinking was generally only 2–5 mm (except for the strong reaction depicted in theme 3-example 2 in this paper). AK was constantly covered with blankets to ensure a comfortable body temperature. Figure 1 depicts AK’s bedside. AK had been living in the ward for eight years, and had gone to the attached school every weekday since he was 6 years old. He was typically educated by four teachers and supported by one school nurse for six hours every weekday, alongside three other students. Individuals from numerous other professions also supported and participated in his care (Table 2).

### **Data collection procedure**

Data were collected from November 2013 to March 2014. Two types of data collection methods were used: observation sessions and group interviews.

### *Observation sessions*

The principal investigator (PI) performed 21 three-hour sessions, for a total of 63 hours over the study period, at AK's side. The observation method, which lacked specific guidelines, was developed along with the study. All data were collected within AK's daily environment. The PI also participated in AK's daily care through assisting caregivers (e.g., changing his body position or diapers, bathing). The PI assigned each caregiver a code to protect their anonymity for ethical reasons. Caregivers' experiences, such as their feelings and the events that occurred in AK's immediate environment, were recorded in the field notes by using key words, figures, and caregivers' codes in order to interpret the context of events and conversations and achieve a "thick description" (Geertz, 1973). Following each observation session, the PI transcribed all notes into field notes outside AK's room.

### *Group interviews*

The group interviews were in a conversational style and recorded digitally, after which they were transcribed verbatim. Additionally, field notes were taken to collect data that could not be recorded digitally, such as caregivers' gestures. Each group interview lasted for 15–45 minutes. In total, 28 participants participated in the group interviews (Table 2). The PI presided over each interview, and expressly told caregivers that the objective of the group interviews was to gather each caregiver's experiences with AK, and encouraged them to share their experiences by emphasizing "the importance of each individual responses, including repeated and contradictory ideas" (Vaughn, 1996, p. 80). Collected data were expected to be diversified by including individuals of various professions.

## **Data analysis**

Our data analysis was based on van Manen's hermeneutic (e.g., interpretative) phenomenological approach (1990). Van Manen (1990) said that "phenomenology is the systematic attempt to uncover and describe the structures, the internal meaning structures, of lived experience (p.10)." Furthermore, he expressed his methods as follows.

- (1) turning to a phenomenon which seriously interests us and commits us to the world;
- (2) investigating experience as we live it rather than as we conceptualize it; (3) reflecting on the essential themes which characterize the phenomenon; (4) describing the phenomenon through the art of writing and rewriting; (5) maintaining a strong and oriented pedagogical relation to the phenomenon; (6) balancing the research context by considering parts and whole. (van Manen, 1990, p.30-31)

Van Manen proposed three approaches to reading (holistic, selective, and detailed). However, he emphasized that "analyzing" thematic meanings of a phenomenon (a lived experience) is a complex and creative process of insightful invention, discovery, and disclosure. "Grasping and formulating a thematic understanding is not a rule-bound process" (van Manen, 2014, p. 320) and "it is in the act of reading and writing that insights emerge" (van Manen, 2014, p. 367).

Additionally, van Manen (1990), of his method, said the following: "its claim to validity as a method of demonstrating truth would be by virtue of itself as methods, as having satisfied certain steps or stages" (p. 173), "discussions and methods and methodology are meant not to prescribe a mechanistic set of procedures, but to animate inventiveness and stimulate insight" (p. 30), and "hermeneutic phenomenological research may be seen as a dynamic interplay among six research activities" (p. 30).

We conducted all six of the research activities described in van Manen's "Methodical

Structure of Human Science Research” (van Manen, p. 30–31, 1990), accounting for their dynamic interplay, by treating his concept of “maintaining a strong and oriented relation” (p. 33) as “maintaining a strong and oriented pedagogical relation to the phenomena” (p. 31). Additionally, we followed three suggestions in “some suggestions for producing a lived experience description” (van Manen p. 64–65, 1990). Precisely, we followed “Attend to how the body feels, how things smell(ed), how they sound(ed), etc.” (p. 65) during data collection in order to prepare for interpretation; “you need to describe the experience as you live(d) through it. Avoid as much as possible causal explanations, generalizations, or abstract interpretations” (p. 64), which served as our theoretical premise; and “describe the experience from the inside, as it were; almost like a state of mind: the feelings, the mood, the emotions, etc.” (p. 64-65), which helped in exploring caregivers’ lived experience.

Van Manen said, “writing distances us from lived experience but by doing so it allows us to discover the existential structures of experience. Writing creates a distance between ourselves and the world whereby the subjectivities of daily experience become the object of our reflective awareness” (van Manen, p. 127, 1990). As such, we repeatedly returned to the time when the phenomena arose in the observation sessions and group interviews and interpreted our data by reading our field notes and transcriptions of the group interviews. This allowed us to expand our interpretation of caregivers’ lived experiences in trying to read AK’s slight movements. Van Manen also suggested “one needs to constantly measure the overall design of the study/text against the significance that the parts must play in the total textual structure” (van Manen, 1990, p. 33). Therefore, the PI’s interpretations were added to the field notes, and we reviewed the accumulated interpretation by comparing them to the original field notes to achieve “balancing the research context by considering parts and whole” (van Manen, 1990, p. 30–31). This was also to ensure the validity of our interpretation.

As the interpretation progressed, the authors realized the importance of the scenes

related to caregivers' experiences of reading AK's slight movements. Further interpretation of these data resulted in the emergence of themes. The scenes and themes are described in the result section.

Trustworthiness was ensured by having specialists supervise the phenomenological analysis. Furthermore, the credibility was ensured by collecting data through both observation sessions and group interviews, having 70 caregivers participate (Table 2), and performing member checking.

### **Ethics**

This study was approved by two ethics committees: those of the participating institution and - Kyoto University (Approval No.1055-1). Furthermore, it was approved by the principal of the special needs school. All study procedures conformed to the principles set forth by the Declaration of Helsinki. We explained the purpose and methods of the study, as well as how we would protect caregivers' privacy and use the results of the study, both verbally and in writing to AK's family and all the caregivers. Participants were told that they had the right to withdraw from the study at any time without penalty. We obtained written informed consent of AK's family and the participants of the group interviews. To ensure that the caregivers were sure of participating in the observation sessions, we gave them two weeks to opt out before the research started.

## **FINDINGS**

In this study, we conducted both observation sessions and group interviews on caregivers' reading of AK's slight movements. In the observation sessions, we observed AK's daily care at AK's side. In the group interviews, caregivers' experiences regarding AK's movements, preferences, and developments in the eight years since he moved into the institution were

discussed.

From our interpretations, four themes emerged as structures of caregivers' lived experience in trying to read AK's slight movements. By considering "AK's physical state and his slight movements" (theme 1) and discovering "caregivers' 'sense of uncertainty' about AK's slight movements" (theme 2), caregivers could decipher "AK's multiple slight movements" (theme 3). "Sharing" (theme 4) was found to be a necessary aspect of these three themes enabling caregivers to read AK's slight movements.

### **Theme 1: AK's physical state and his slight movements**

In the following short scenes, the limitations of AK's physical ability and how caregivers considered this ability while reading AK's slight movements are clearly illustrated. Besides the slightness of his movements, the fact that AK's body was always covered with bedding, even while he was in a wheelchair, made it difficult to observe AK's slight movements. In the following scenes, we provide examples of AK's sporadic, slight movements and our interpretations of their reading of these movements.

*Caregivers were discussing the bed position for short-stay patients.*

*Movement of AK: Both eyes open, with pupils in the middle of the eyes. His face turns to the head of the bed (where the inhaler is located), with his eyes shifting somewhat to the left, facing the nurses, whereas they usually move to the right. AK's gaze remained where caregivers were a little while ago. AK's gaze is slight and slow with poor reproducibility, and it causes difficulties for caregivers to judge whether their eyes and AK's met and to identify what AK was looking at.*

*AK's neck moved to the left, towards his caregiver, which was noticed by the PI. His irises moved in the same direction. Although the movement of the irises was slow, slight, and could not follow the caregiver's movements accurately, it was thought to be a purposeful movement in response to the environmental stimuli because the irises' positions differed from normal (2<sup>nd</sup> session).*

To identify the purposefulness of the movements, caregivers at first had to be aware of AK's slight movements and relate those movements to environmental stimuli. However, AK's physical ability had insufficient moving range and speed to accurately follow the changes in his environment.

Interpreting this theme, we found that, in reading AK's movements, it is important to consider not only whether the movements themselves are present, but also the phenomena before and after those movements.

## **Theme 2: Caregivers' "sense of uncertainty" about AK's slight movements**

In this theme, the diversity of caregivers' perspectives towards AK's slight movements was revealed. For instance, Caregiver-M's experience of AK's movements were remarkable because the caregiver's "sense of uncertainty" could be verbally described as a fear of AK's 'eye power,' as shown in the dialogue with the PI later in this section.

AK was diagnosed as having a VS/UWS, which meant that he should not have had the ability to make purposeful responses. Caregiver-Y reported AK's normal state as "[his] eyes are almost always fixed in the upper right position, so I think it is not easy to identify his purposeful movements" (1<sup>st</sup> session). On the other hand, Caregiver-K said "I believe AK's eye (AK had a squint) and my eyes met. If I take his physical ability into consideration though...." (2<sup>nd</sup> session). When the PI asked Caregiver-P if AK's and her eyes had met, she said, "Hmmm,

it's hard to say. I don't know. I wish I could say yes though, well, I don't know" (3<sup>rd</sup> session). Furthermore, Caregiver-G said, "I don't know. But there was a medical judgment that AK could not see, when he came here from a hospital." (1<sup>st</sup> group interview). In asking caregivers this same question, the PI had the following exchange with Caregiver-CC:

*[PI to Caregiver-CC:] "Actually, you are still the only person who has told me 'my eyes met AK's.' Some people said there is a possibility, if they view him in a favorable light."*

*[Caregiver-CC:] "Are you sure? I think my eyes met his eyes for sure. Ah, maybe, that's because I'm strange though. I'm different from the others. So, I might be under the wrong impression... I'm strange. My thinking way is different from others' here. So, maybe it's just my imagination...One other caregiver said 'AK is like Helen Keller. He can't see. He can't listen. I don't think so.' I think she is wrong. If what she said is true, it's hard for us isn't it? If he can't listen to whatever we say... if he can't listen to what we say during the care, it would make me feel empty." (20<sup>th</sup> session).*

Other caregivers reported that it was difficult to judge whether AK's and the caregivers' eyes actually met. Indeed, caregivers' opinions on this topic rather differed. In the following scene, Caregiver-M shared the changes in her lived experience related to AK.

*When Caregiver-M was tidying up the room, she asked the PI "Don't you feel like you are being watched?" The PI said, "Do you feel it from AK?" [Caregiver-M:] "I think so. When I ate some candies, and made a crunching sound during the night shift, I felt scared." [PI:] "Scared?" [Caregiver-M:] "I was eating Pocky [the name of a candy stick], there—"[Caregiver-M pointed to the right side of the table beside AK's bed; see Figure 1. Note that caregivers tried to spend as much time in the room as possible*



*during night shifts, even during their breaks]. “—and AK strongly stared at me for a little while...My body was frozen. I felt scared because I felt AK’s ‘eye power,’ you know?” (2<sup>nd</sup> session).*

By repeatedly reviewing the field notes from the sessions, the “sense of uncertainty” that caregivers experienced was gradually revealed. For example, in the 3<sup>rd</sup> session, this “sense of uncertainty” made caregivers indecisive regarding AK’s eye movements. In contrast, in the 2<sup>nd</sup> session, it caused Caregiver-M some fear. Although Caregiver-M initially kept her fear to herself, her sharing and discussing them with the PI in the 2<sup>nd</sup> session opened the possibility of reading AK’s slight movements; by the end of the 2<sup>nd</sup> session, Caregiver-M’s fear had crystallized in the form of the phrase “eye power.” Humans tend to be able to more easily handle invisible phenomena by defining them—in this way, Caregiver-M’s certainty was increased by having her verbally express her fear.

### **Theme 3: AK’s multiple slight movements**

#### **Example 1: Hiding AK’s pulse oximeter as a test**

The following scene began as a result of a discussion that had occurred both during prior observation sessions and the group interviews. In listening to this discussion among other caregivers, Caregiver-FF joined in and spontaneously began a test to try to bring out AK’s purposeful movements by hiding his pulse oximeter. The pulse oximeter was indispensable for AK, functioning both as a life-support system as well as allowing caregivers to monitor his physical state such as heart rate and oxygen saturation.

*[Caregiver-X:] “Before, you said to me that AK really looked at the pulse oximeter. I do not mean to disagree with your opinion, but we can think of other possibilities too.*

*AK might be looking at it because the pulse oximeter is the only electric device that has lights or with changing lights [according to his pulse] in his view. Another possibility is that the most comfortable position for AK's neck is when he is facing the monitor but is not really looking at it. You can think of many ways, can't you? But maybe, like you said, AK is concerned or anxious about it, and is doing his best to maintain his oxygen saturation."*

*Caregiver-FF was nearby during this conversation, and she moved AK's inhaler slightly so that the pulse oximeter was not visible to AK (Figure 1). Then, the peaks of AK's cheeks suddenly drooped, and the corners of his mouth sagged slightly. AK looked angry to the PI. [PI:] "when AK does not like something, or is disappointed, do you think this line [cheek to jaw] changes? Do his cheeks droop? Do the corners of his mouth sag? If I ask my son 'Make an angry face,' his cheeks do something similar to what AK just did. The peaks of his cheeks drooped, and the cheek line became an oval. If I ask him 'Smile,' then his cheeks pop out and the face becomes round. I think AK's facial muscle should move just like other people."*

*[PI to AK:] "You want to look at the pulse oximeter, don't you? Let's put it back. What do you think?" AK blinked. Once the PI moved the inhaler aside and returned the pulse oximeter to where it usually was, AK's drooping cheek line rose up again and he started looking at the pulse oximeter (14<sup>th</sup> session).'*

Caregiver-FF's hiding the pulse oximeter by using AK's inhaler made it evident that not only sharing caregivers' "sense of uncertainty" but also performing tests with objects in the immediate environment was an effective way of identifying purposeful movements. Among the three caregivers who were paying attention to AK's movements, only the PI, who was right in front of AK (Figure 1), detected his movement. This demonstrated how difficult it was to

identify AK's purposeful movements because of their slightness.

On the other hand, although we could not make any conclusions about AK's reaction to the hiding of his pulse oximeter, caregivers were able to share their "sense of uncertainty" as well as their interpretations during the process. The significance of the scene was how the test appeared to overturn caregivers' common interpretations of AK's movements based on objective data (e.g., how '[his] eyes are almost always fixed in the upper right position, so I think it is not easy to identify his purposeful movements'; Caregiver-Y, 1<sup>st</sup> session).

### **Example 2: A change in location for AK's pulse oximeter**

Although we tried to identify AK's repeated or strong movements throughout all the observation sessions, the 17<sup>th</sup> session was the only session in which AK exhibited strong movements.

A sensor for the pulse oximeter was continuously attached to AK's fingertip. AK's room was set up for patients with the most severe multiple disabilities in the institution, who required medical care (e.g., management of respirators, tube feeding). Since it was difficult for these patients to make sounds and gestures to express their intentions, there was no nurse call system in AK's room. Instead, nurses would react to the alarm sound of AK's pulse oximeter, which would prompt them to attend to AK and check for any problems.

*After the previous observation session (16<sup>th</sup> session), the type of respirator changed, the topmost shelf was removed, and the pulse oximeter, which had been next to the respirator, was lowered about 20 centimeters (Figure 1). However, the bed's height was the same as before, so the pulse oximeter was no longer visible from AK's position. AK's position was then changed, such that he was lying on his side, with his face directed higher than usual.*

*[PI:] "Should I move the direction of your face?" AK blinked noticeably. [PI:] "Ok,*

*I'll change the direction a bit. Just like usual.*” AK blinked. Gently, the PI changed the direction of AK's face to the usual direction (i.e., with his right cheek to his pillow). AK's eyes moved toward the rack around his head, and then to where the pulse oximeter had been a month ago. [PI:] “Are you looking for the pulse oximeter?” AK blinked noticeably. [PI:] “Are you tired from looking for it?” AK blinked. [PI:] “Ping-pong?” [this sound is often used on quiz shows to indicate correct answers] AK blinked noticeably. It was a powerful blink at the just right time. [PI:] “It's here. Can you see it? Beep, beep, beep.” PI traced a line in the air from AK's side to the pulse oximeter. PI pointed out the pulse oximeter and said, “It's right here.” AK maintained his eyes line and showed no reaction. [PI:] “Can't you see it?” AK blinked. [PI:] “Ok, shall we lift it up a bit?” [After getting permission from a caregiver], PI lifted the pulse oximeter slightly. Then, AK blinked noticeably twice. [PI:] “There it is. Isn't that nice. Is this [pointing to the pulse oximeter] your friend?” AK turned his irises upward so that only the whites were shown and stayed like that for few seconds before lowering his irises back and blinking. [PI:] “Ping-pong?” AK blinked. [PI:] “It's your friend, isn't it? You found the meaning of the ping-pong, didn't you?” The PI waited for a fleeting time for AK's movement and then said, “When you become uncomfortable, your pulse oximeter calls caregivers for you.” AK blinked. [PI:] “That's why it's your friend?” AK blinked. [PI:] “That's right, isn't it?” AK blinked (17<sup>th</sup> session)

In example 1, Caregiver-X, FF and PI shared their experiences concerning AK and his pulse oximeter, whereas in example 2, AK's strong and repeated movements were observed.

#### **Theme 4: Sharing caregivers' sense of uncertainty**

According to AK's medical records and briefings in the ward (8<sup>th</sup>, 9<sup>th</sup>, and 10<sup>th</sup> sessions), the

“sharing” of caregivers’ “sense of uncertainty” about AK’s slight movements, described above, were not given any attention. Caregivers said “we would like to share information about AK with staff who cared for AK when he was admitted to the institution.” The first group interview was set on a day on which caregivers who had known AK since his first day at the institution were working. After every group interview, these caregivers’ conversations about their experiences of AK’s care continued after they returned to the wards in which they worked or tidied up, as well as in subsequent observation sessions (themes 2 and 3).

Caregiver E said “this is how I would like to share our ‘sense of uncertainty’ in the care for AK.” She also said, ‘we really felt that it was difficult to read AK’s slight movements, honestly, so I had given up. I noticed that was wrong (14th session).’

In interpreting theme 3-example 1, we found that caregivers have considerable difficulty in making judgments regarding the purposeful movements of a child with severe brain injury. In this example, hearing the discussion between caregiver-X and the PI, Caregiver-FF conducted a test to determine the purposefulness in AK’s movements by hiding AK’s pulse oximeter. From Caregiver-FF’s conducting of the test, we can infer that she had some interest in reading AK’s slight movements. In this way, sharing experiences through discussion might have encouraged caregivers to become more interested in AK and to read AK’s slight movements.

“Sharing” these repeated and strong movements (theme 3- example 2), which were completely the opposite of his normal physical state, might have helped caregivers to increase certainty in their ‘sense of uncertainty.’ It can be suggested that the “sharing” in this study boosted the caregivers’ interests and awareness, and the PI would never have noticed the relationship between AK and his pulse oximeter without the “sharing” present in the previous themes.

## **DISCUSSION**

In this section, we discuss the 4 themes by focusing on caregivers' "sense of uncertainty" and "sharing" to disclose caregivers' lived experience in trying to read AK's slight movements, as well as clarify how "sharing" helped caregivers read AK's slight movement.

### *"Sense of uncertainty"*

Caregivers noticed their "sense of uncertainty" through sharing their experiences (as in Theme 2). The "sense of uncertainty" partly arose because of the gap between caregivers' lived experience and what they knew about AK based on his objective data, and difficulty in finding AK's repeated or strong movements due to his severe physical state. Additionally, caregivers had no way of confirming AK's will or thoughts. This "sense of uncertainty" became evident when they expressed their thoughts about AK's gaze, such as "...It's hard to say. I don't know. I wish I could say yes, though, well, I don't know" (3<sup>rd</sup> session) or 'I believe AK's eye (AK had a squint) and my eyes met.'" (20<sup>th</sup> session). When it comes to judging AK's state, caregivers clearly expressed a 'sense of uncertainty.'

Caregiver-M's "sense of uncertainty" is particularly noteworthy. She asked the PI, "Don't you feel like you are being watched?" Her "sense of uncertainty" was likely caused by the gap between her lived experience and his objectively known physical state. Caregiver-Y actually reported, "[AK's] eyes are almost always fixed in the upper right position, so I think it is not easy to identify his purposeful movements." Considering this report and AK's diagnosis as VS/UWS, Caregiver-M's feeling of fear caused by the perceived power of AK's eyes was one case in which a caregiver's "sense of uncertainty" was clearly stated and obviously caused by gaps between the subjective and objective data. Insufficiency of objective evidence has been highlighted as a potential problem in observing the purposeful movements of children with severe brain injuries. One study (Greenhalgh et al., 2014) claimed that "as serious illness is lived, evidence based guidelines may become irrelevant, absurd, or even harmful (most

obviously, in terminal illness)” (p. 3), because “evidence based guidelines often map poorly to complex multimorbidity” (p. 2). Overall, children with severe brain injuries should be regarded as being in a state of “complex multimorbidity” and “serious illness,” which, coupled with objective data on AK’s physical state, made Caregiver-Y assume that AK did not have the ability to make purposeful movements.

AK exhibited repetitive and strong movements (Theme 3-example 2) only once during the 63-hour observation period. These were possibly purposeful, and if AK could make purposeful movements, his consciousness state might have changed from VS/UWS to MCS. In a previous study, van Erp et al. (2015) stated that confirming visual following is key for preventing a misdiagnosis of MCS as VS/UWS. In this study, despite the slightness of AK’s movements, caregivers’ attempts to confirm his visual following in fact helped them identify unusual movements that may be regarded as purposeful (Theme 1). In other words, the difficulty in identifying his purposeful movements through confirmation of visual following arose from AK’s total lack of physical ability—any movements made were so slight that caregivers could not easily detect them in relation to the surrounding environment. In theme 1, we deeply considered AK’s physical state in relation to his surrounding circumstances. His eyes were usually fixed in the upper right position, and AK had the physical ability to move his neck slightly. Some caregivers were at AK’s bedside, and his eyes moved along with his neck in their direction. Unless the entire scene was considered holistically, these movements would not, on their own, indicate purpose.

Although caregivers actually carry out holistic observations while trying to read the slight movements of children with severe brain injuries, the subjective aspects of these observations are buried because objective evidence is prioritized. A review (Greenhalgh et al., 2014) has suggested the importance of “the patient’s experience of illness and the real life clinical encounter for different conditions and in different circumstances” (p.4) in seeking real

evidence-based medicine, which “makes the ethical care of the patient its top priority” (p.5). However, we cannot ever directly obtain the actual experiences of children with severe brain injuries. Thus, in aiming to improve care for children with severe brain injuries, we should investigate the experiences of caregivers who are seeking to understanding these children.

### ***“Sharing”***

We would like to discuss the significance of “sharing.” Caregivers’ “sense of uncertainty” is difficult to measure and categorize. For example, while the opposite of a “sense of uncertainty” would be a ‘sense of certainty,’ we cannot simply divide all caregivers’ feelings’ into these two categories. Some caregivers do not even notice their own ‘sense of uncertainty,’ and the actual level of uncertainty varies among caregivers. These unclassifiable and unmeasurable data should receive considerable attention in order to overcome the limit of objective data by giving caregivers new knowledge and perspectives on individual care.

In theme 2, caregivers’ “sense of uncertainty” was gradually revealed, and the variety of degrees of uncertainty was evident in their words. Although Caregiver-G, in answering a question asked by the PI, revealed that he thought that AK did not have visual abilities, Caregiver-M spontaneously shared her lived experience of fear caused by AK’s slight movements. In this way, caregivers shared their “sense of uncertainty” through discussion and interpretation. Through sharing, caregivers accumulated vicarious experiences to aid in their own practice.

In theme 3-example 1, wherein Caregiver-FF hid AK’s pulse oximeter with his inhaler, we found that sharing a “sense of uncertainty” through discussion was not the only way of reading AK’s slight movements. In fact, it was possible to test for this movement in a way that could be easily done by anyone. However, among the three caregivers who were paying attention to AK’s reactions, only the PI, who was right in front of AK (Figure 1) detected his reactions.



This demonstrates how difficult it was to identify AK's purposeful movements because of their slightness. It further suggests that we should not aim to identify purposeful movements directly, but sharing caregivers' experiences of trying to read those movements. In other words, although we could not conclude that AK was in fact looking for his pulse oximeter, the testing process allowed caregivers to further share their "sense of uncertainty" and reflect on their interpretations of reading AK's slight movements.

Deciphering AK's multiple slight movements through hiding his pulse oximeter was also a way of confirming the validity of the objective medical judgments that AK could not hear or see. Realizing and having a "sense of uncertainty" changed caregivers' perspectives by ridding them of preconceptions based on objective data. This change was evident in their increasingly active involvement in deciphering the implications of AK's slight movements, which ultimately led to their identifying possible such movements. "A more positive character of the phenomenological approach is that it constitutes a determined attempt to enrich the world of our experience by bringing out hitherto neglected aspects of this experience" (Spiegelberg 1982, p.717).

We would like to discuss how difficult to assess children with severe brain injuries with an objective scale named the Coma Recovery Scale-Revised (CRS-R) (Giacino, 2004; (Giacino, Kalmar, & Whyte, 2004). Although it was "demonstrated to have significantly higher sensitivity to detect MCS patients, as compared to the GCS [Glasgow Coma Scale (Teasdale & Jennett, 1974)], the FOUR [Full Outline of UnResponsiveness (Wijdicks, Bamlet, Maramattom, Manno, & McClelland, 2005)] and the WHIM [Wessex Head Injury Matrix (Shiel et al., 2000; Wilson, Elder, McCrudden, & Caldwell, 2009)] (Schnakers et al., 2008, p. 786)," there are some problems with using such an assessment with children who have severe brain injuries. For example, one of the check items on the CRS-R is "Object-Related Eye Movement Commands: Present 2 common objects simultaneously and approximately 16 inches apart

within the patient's field of view. Ask the patient to look at the object named (i.e., 'Look at the [name object]'). Next, reverse the positions of the 2 objects and ask the patient to look at the same object again (i.e., 'Look at the [object]')." This item might not be applicable to children whose language level has not reached the necessary level of recognizing these instructions. Considering the time that AK received his injury, his language level was likely not at the level to answer this question. Accordingly, not only the extent of brain injury, but also the development of language and cognitive levels acquired should be considered when assessing children with severe brain injury.

In contrast to this objective approach, accumulating and sharing caregivers' experiences via the phenomenological approach might help in deciphering the implications of slight movements of children with severe brain injuries, which can help prevent misdiagnosis between VS/UWS and MCS by bridging the gap between medical data and caregivers' experiences. Additionally, objective evidence about children with severe brain injury is currently poor (Greenhalgh et al., 2014), which is partly caused by the variability in children's language and cognitive development.

### ***“Sense of uncertainty” and “Sharing”***

By reviewing each theme in light of 'sharing,' the importance of “sense of uncertainty” and “sharing” was highlighted. Caregiver M was aware of her own 'sense of uncertainty,' and realized that she was not the only one who had it (see themes 2 and 3). However, this “sense of uncertainty” was never included in the medical data or briefings in the ward (8th, 9th, 10th session) because of its inherent subjectivity. With the absence of opportunities to share, caregivers had been missing the chance to reflect on this 'sense of uncertainty.' Possibly, the birth of a “sense of uncertainty” is what leads to emotional change. Polanyi (1958) said that complete objectivity is a false ideal, and it is important to understand that personal knowledge

can influence and enhance the objective. Since “we know more than we can tell” (Polanyi, 1967, p. 4), it will be useful to share caregivers’ experiences such as “sense of uncertainty” and to try to explain their experiences.

When a “sense of uncertainty” begins to rise, caregivers should realize the actual state of children in VS/UWS—who are not supposed to have the ability to make purposeful behaviors in response to environmental stimuli—may, to some extent, be different from what should be assessed. Sharing this “sense of uncertainty” helps caregivers to confirm whether that sense is based on mere speculation or actual phenomena in their environment. This can help in changing a “sense of uncertainty” to a sense of certainty, as described in theme 2, wherein a caregiver shared her experience of emotional changes caused by AK’s slight movements, which led her to conclude that it was due to AK’s “eye power” (*Mejikara* in Japanese, which means the power expressed through one’s eyes). Thus, caregivers’ “sense of uncertainty” was interpreted through sharing, which led to a broadening of their perspectives on AK and AK’s slight movements (Theme 3-example 1). Consequently, it motivated caregivers to confirm AK’s intentions through hiding his pulse oximeter whether his movements were purposeful or not.

Thus, we believe that “sharing” refers to not only the expanding of each caregiver’s perspectives through accumulating their experiences, but also to the interpretations generated by multiple caregivers. Caregivers gain more opportunities for identifying strong movements such as those in theme 3-example 2 and can broaden their perspectives by making judgments collectively, rather than individually, and by attempting to read the slight movements of children with severe brain injuries based on not only the presence or absence of children’s purposeful movements, but also the continuity of a “sense of uncertainty” to a ‘sense of certainty’. The results also showed that sharing was boosted by caregivers’ intentionality in reading AK’s slight movements, as well as caregiver’ detailed narratives of their own

experiences, which enabled other caregivers to vicariously experience them. “Sharing” also helped indicate the significance of the pulse oximeter for AK by reading AK’s slight movements. One example—‘it’s [AK’s pulse oximeter] your friend, isn’t it?’ (17<sup>th</sup> session)—was shown in theme 3-example 2.

Belk (2010), in his theoretical review, claimed that sharing was overlooked due to popularization, and suggested that further research on sharing experiences is needed. Since the “sharing” in our study only pertained to the sharing of caregivers’ experiences and was found to have the potential to improve care for children with severe brain injuries, we will attempt to continue our research.

### ***Limitations***

The limitation of this study was that this study conducted in a single ward in a single institution. Thus, we cannot generalize the results of the study. This is particularly true for children with severe brain injuries, whose states vary widely with the cause of their brain injuries and the age at which they were injured. Additionally, a philosopher whose specialty is phenomenology and exegetics has joined our team and is involved in developing our analysis methods [JSPS KAKENHI Grant Number JP17K12381]. Despite these limitations, our study offers new perspectives for care and research. We will continue our research in order to further understand the children with severe brain injury and “sharing” caregivers’ experiences, which will help in applying our results to other situations.

## **CONCLUSION**

We disclosed caregivers’ lived experience in trying to read slight movements in a child with severe brain injury. “Sharing” helped caregivers in considering “AK’s physical state and his slight movements,” discovering “caregivers ‘sense of uncertainty’ about AK’s slight movements,” and deciphering “AK’s multiple slight movements.”

Moreover, a caregiver's "sharing" of his/her experience allowed other caregivers to become aware of their "sense of uncertainty," as well as to vicariously experience and interpret phenomena in the care of a child with severe brain injury.

### **RELEVANCE TO CLINICAL PRACTICE**

The four themes that emerged in this paper might be useful for assessing, guiding, and promoting caregivers' use of sharing when reading the slight movements of children with severe brain injury. In particular, our results implied that "sharing" was more useful when caregivers conducted it based on the following three approaches: (1) sharing in order to consider caregivers' lived experiences; (2) sharing and interpreting multiple caregivers' experiences of various feelings, such as a "sense of uncertainty" and its shift to a "sense of certainty" about AK's slight movements; and (3) sharing to store these interpretations as caregivers' own lived experience for future use. "Sharing" might help caregivers observe more details about AK, which in turn opens up the possibility for caregivers to provide AK with better care.

We suggest that "sharing" can be applied to other children with severe brain injuries, and not just AK. We believe that our results will also stimulate discussion about the care of such children beyond Japan's borders and culture, which may contribute to the creation of individual care plans best suited to each patient's states, needs, and context. We also believe that caregivers should more openly share their lived experience with each other in order to decipher the implications of slight movements in such children. Thus, we hope that our results will be internationally accepted. Furthermore, as sharing requires no additional funds or even a new system of care, it is not restricted by financial situation or availability of medical equipment and facilities. Optimizing care for patients whose will cannot be confirmed directly is challenging, not only in Japan but also worldwide. In order to improve such care, our results

strongly suggest that we should consider caregivers' lived experience alongside the objective data emphasized in medicine and nursing.

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**FIGURE LEGENDS**

Figure 1. AK's Bedside: *Position of caregivers, principal investigator, and medical equipment*