

# Phenomenological Analysis of a Japanese Professional Caregiver Specialized in Patients with Amyotrophic Lateral Sclerosis

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**Abstract** The present article is based on a interview with a Japanese experienced caregiver who specializes in patients with amyotrophic lateral sclerosis (ALS), which generally leads to the locked-in syndrome (LIS). Professional caregivers for ALS patients with ventilator experience two particular temporalities in their practice. First, they must monitor the patient continuously during a seven-hour stay. Because a single problem in the ventilator can have fatal consequences, the care of an ALS patient with a ventilator (who can neither speak nor push the nurse call button) requires long periods of sustained concentration. Second, trying to understand the signs of a patient with a ventilator sometimes requires three hours to go through ten alphabets. In addition to the huge effort that such communication requires, caregivers must complete the meaning of the signs with their imagination: the ten alphabets are not sufficient to understand what the patient really wants to say. This imaginative capacity, however, is based on a long relationship, which started when the patient was still able to speak and move. That is why, as this article will show, even when a patient has entered total LIS, the caregiver can continue to realize his or her wishes.

**Keywords** ALS · Caregiver · Ventilator · Phenomenology · Qualitative research · Locked-in syndrome

## Background and aim

Amyotrophic lateral sclerosis (ALS) is a fatal neurodegenerative disease with sudden onset, rapid progression and complex disabilities because of progressive muscle weakness. The patients gradually lose speech and finally respiration. Sooner or later, the patients become totally dependent on caregivers. If it is the family members who are the principal caregivers, they undergo considerable physical and psychological distress [1, 2].

With rates clustering around 25 and 30%, ALS patients' use of tracheostomy with invasive ventilation is much higher in Japan than in Europe and the United States [3–6]. These patients often continue to live in their own home even when they do not have a family and are by themselves. This is enabled by the fact that, in many regions of Japan, the social sector provides sufficient services, so that the affected persons do not depend on their families. Historically, in Japan, it was the patients and their families who struggled for the amelioration of social support during last two decades, and there now is a system that makes it possible for ALS sufferers to live at home with a ventilator [7].

In that context, there are many professional caregivers, often trained by members of the Japanese ALS Association, who are responsible for patients' daily lives. It is known that not only patients, but also caregivers suffer from the burden and the low quality of life that results from receiving home-based care in the absence of sufficient social support [8]. However, a

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professional caretaker's experience is different from that of the family, who is frequently overcome by despair and suffer from the change in their daily lives brought about by caring duties [1, 2]. In Japan, professional caregivers can offer home-based care for many hours and enable the daily lives of such patients; as is well known, ALS patients require long hours of care [9].

Our study will contribute to the study of ALS care, because there is practically no research on the professional caregivers or visiting nurses who provide home-based care for ALS patients. A MEDLINE search showed 35 articles with the keywords "Amyotrophic Lateral Sclerosis" and "Home Nursing," and almost all of them were about family caregivers rather than about professionals. With the keywords "Amyotrophic Lateral Sclerosis" and "Nursing", three articles appeared and only one of them was a recent publication on a Japanese case. [10] To the best of our knowledge, there is no qualitative research on the techniques and skills of professional caretakers who care for ALS patients with a ventilator at home. It is well known that ALS patients are inclined to fall into depression [11]. However, our research suggests, with sufficient support, ALS patients can enjoy a happier life even with the ventilator.

In Tokyo and in some other regions in Japan, ALS patients with ventilators can use services 24 h a day [12, 13]. Such prolonged care brings about a particular relationship between patients and caregivers. When LIS arises in the advanced stages of ALS, the caregiver operates in the framework of a long period of previous care. It is largely due to the existence of such previous care that an ALS patient lives long enough to reach the locked-in state. The present article describes in detail the structure of the intersubjectivity that develops in the framework of such home health care of persons with ALS and LIS in Japan. It is important to point out that a phenomenological analysis of the care situation of a patient who entered LIS suddenly (most commonly due to a brainstem stroke) rather than gradually (as due to ALS) would offer a different picture; it has never yet been carried out.

The analysis developed here is based on a interview with Ms. F., a Japanese caregiver, or home health aide, who has specialized in caring for ALS patients. She runs a company with four other caregivers and had seven ALS clients when we interviewed her.

## Method and Structure of the Article

### Data Collection

This article is a part of a larger phenomenological qualitative research on home health care. We interviewed one doctor, 11 nurses, and one home health aid, and observed the practice of some of them. We here focus on an interview with a professional caregiver who specializes in caring for ALS patients. In this research with caregivers, we conducted non-structured interviews that lasted from 90 to 120 min. The interviewees were invited to describe freely their daily practice; we asked questions when their narrative was not clear. We chose the non-structured interview because the practice of a visiting nurse is very varied and complex. In our experience, it usually goes beyond what the researcher anticipates, and raises challenges that rarely match pre-established descriptive and interpretive frameworks. Each interview was transcribed verbatim.

### Data Analysis

We attempted an interpretative phenomenological analysis, describing the structure of a caregiver's individual experience of caring for ALS patients. To reconstruct the unique and irreplaceable structure of each care, we focused on each individual caregiver and analyzed in detail the interviews conducted with them. When applied to the analysis of empirical data, phenomenology becomes a method to describe the *dynamics* of a caregiver's practice or patient's experience *from inside* their point of view. In this type of research, the investigator examines each datum (interview or observation) as a whole and describes the structure of an individual professional's practice. This brings to light the uniqueness and value of each practice, which is not reducible to standardized care. Insofar as the researcher adopts the standpoint "from the inside," the analysis necessarily leads to describing the unique structure of a singular event, in contrast with methods that adopt the "outside" standpoint, compare larger amounts of data, and generalize them into abstract concepts. Because each caregiver and each patient has their own experience and style, the detailed examination of individual cases can fill in gaps left by larger-scale quantitative research. We adopted the applied phenomenological approach developed by Yumi Nishimura, which is largely based on the work of Maurice Merleau-Ponty and Edmund Husserl [14]. Such phenomenological analysis of an individual

case may give vivid and embodied meanings to the general concepts offered by other methods.

Indeed, in the phenomenological perspective, we are not satisfied with merely enumerating the important elements of the described phenomenon. Rather, we try to exhibit the entire structure of the practice of *one practitioner* in its coherency. The main goal of such approach is to demonstrate how these elements are connected to each other and how they form a total and unified practice of care. That is why we try to describe linearly and step by step the several elements of care with their internal logic, and also why the discussions are incorporated into the results.

In the first section, we describe the particular features of the ALS caregiver's daily practice, which turns out to be fundamentally different from the practice of hospital nurses. Its distinctness resides in its long duration (section "[Data collection](#)") and its intensity (section "[Data analysis](#)").

The second section is focused on communication. How is communication achieved when the patient using a ventilator cannot speak and can only move their eyelids? What are the sui generis features of this type of circumstance? These are the subjects of section "[The time lag in communication and the risk of a fatal accident](#)". In 2.2, we describe the accumulation of care as a condition that enables communication with the ventilated ALS patient, and in 2.3, the particular difficulties found in this communication.

The third section describes the environment created by the special circumstances of care, as well as the dynamics that enable the realization of the patient's personality despite almost complete paralysis. Section "[Reading the true meaning](#)" explains how a caregiver conforms to each patient's character and creates an appropriate environment of care. Section "[Historicity in the alphabet board](#)" depicts how the caregivers' teamwork pursues and accomplishes each patient's wish and personality. Finally, in section "[The difficulty of communication](#)" we observe that, even in the stage of total LIS, a patient can realize his or her wishes and subjectivity when caregivers properly arrange the environment, and help not only the patient but also the family members.

### Caring for Patients Who Use a Ventilator

Ms. F., an expert professional caretaker in her forties runs a company of caregivers who specialize in caring

for ALS patients. She herself is an expert caregiver with over ten years of experience. After she became a professional caregiver, she was trained by her ex-client Misao Hashimoto (a famous ALS patient in Japan, user of a ventilator for decades, and former president of the Japanese ALS Association), and she was regarded as a specialist in ALS. We had a conversation at a business office in Tokyo in 2014.

To begin with, we must bear in mind the difference between a caregiver and a visiting nurse. In Japan, a visiting nurse generally looks after a patient once a week and stays for an hour in his or her home; in contrast, professional caregivers like Ms. F. operate every day for several hours. With their help, a patient with a ventilator who is almost completely paralyzed can survive alone at home. This is the case of most Japanese ALS patients. Thus, the caregiver is someone who enables the patient's life itself, which can be said to depend on a complex technology of care. Modes and experiences of subjectivity and intersubjectivity vary with those technologies. We will try to articulate three modes of life in the dynamics of ALS patient care.

Ms. F: I attentively monitor all the moments during the stay. For example, I watch and ask myself, "Is there not dribble?" Our care really requires attentive observation. Even during my lunch break, I have to care for the patient if I hear a noise emanating from the ventilator. A stay requires [kichinto] continuous watching attentively for several hours. (8: The number following the quotations indicates the page in the transcription of the interview)

With a ventilated patient deprived of verbal communication, machine trouble could quickly lead to death. The caretaker has to "immediately react if there is something wrong." The repeated verb "watch" points to the distinctive characteristic of caring for an ALS patient who cannot speak. Paradoxically, it is not doctors or nurses, but caretakers who are *medically* responsible for the patient's life because they are always with the patient and may notice an accident. That is why the tone of the interview with Ms. F. had a particular tension – especially when compared to my interview with a nurse who often cares for ALS patients, and considers that they require less attention than cancer patients.

Ms. F repeats the adverb "attentively [kichinto]." This underlines the style of her practice. Contrary to

the visiting nurse who see the patient in a short visit, a caretaker stays for several hours and watches continuously, without rest. To keep the patient alive, the care must be “attentive.” The adverb “attentively” indicates the quality of this intense and long observation. It is as if the duration of the caregiver’s sustained attention was multiplied by the intensity of the care.

Thanks to such features of the caregiving practice and the depth of understanding caregivers thereby gain, patients place more confidence on their daily caretaker than on their doctors or nurses. Duration and intensity of care are transformed into trust. The community of ALS patients and their caretakers is based on this particular trust; and insofar as it is the foundation of trust, the continuity of care gains ethical relevance.

#### The Time Lag in Communication and the Risk of a Fatal Accident

Ms. F.: You may give up if you can go home in 1 or 2 hours [as a visiting nurse], but we cannot [do something like that], because [*yappari*] we are responsible for the life of the clients. We must hand the baton of [*tsunagete*: connect] life [to the next caregiver] and do what we have to do and hand the baton of life [*tsunageru*] to the next caretaker. When there is some incident, we [must] . . . [The client] cannot say “help me”, because [*yappari*] there is a time lag, for example, in the reading of their signs. It is why we must study a lot to understand [patients] and judge what happens in an accident. (9–10)

Communication with the ALS patient using an alphabet board (also called spell board) depends on the caretaker’s ability to read the signs, but implies a time lag because of its difficulty. At the same time, an accident immediately places the patient’s life at risk. Because caretakers are “responsible for the patient’s life,” they cannot give up despite extreme challenges in communication (enabled with the help of some device). The impossibility to give up is a recurrent subject in the interview with Ms. F. Communication with a “time lag” and the urgency concerning life require absolute patience and understanding on the caregiver’s part. Heterogeneous rhythms such as slowness, urgency and long duration, are combined and magnified in a single situation. Such polyrhythm entirely permeates the environment of care; the continuity of care that unifies various

temporal rhythms is one of its major features. The home health aide is someone who integrates the polyrhythms.

In the last few lines of the quotation above, the grammatical subject is ambiguous: first Ms. F. says “we”; however, soon the client becomes the subject, and in the last sentences she returns to the “caregivers.” This ambiguity comes from the distinct difficulty of ALS. Because patients cannot spontaneously verbalize what they want to say, the caregiver has to fill in gaps of signs emitted through some device. It is as if the caregiver herself uttered the SOS in place of the patient, and received it as well. This grammatical ambiguity shows well the style of communication between patient and caregiver.

“*Yappari*,” variously meaning “in spite of this”, “very often” or “because,” and frequently used in this interview, signals the particular plight that ALS imposes and expresses the modes of communication and care. Both caregivers and patients must behave under the peculiar conditions of this disease, which “*yappari*” signals. Furthermore, such conditions even select the type of caregivers, and dictate the singular quality and ability of care that circumstances demand.

Researcher: “You said that it is the question of responsibility.”

Ms. F.: Ah, yes. Because [*yappari*] I founded a company, and because [*yappari*] I have to manage the employees, it is required that we must not say “I do not know”. And, if my employees do the right thing to save the life, I tell them “You can do that because it is the right thing. I will take the responsibility.” These are two important things. Yes [*yappari*], patients who depend on the ventilator encounter of course [*yappari*] immediately death if the machine drops, because they do not have spontaneous respiration. We must always be prepared for such a situation. [...] The care giver is always there. If something happens, it is always the caregiver who is beside the patient. . . . Yes, if [*yappari*] something happens, we must react attentively in order that this “something” does not become a fatal accident. (11)

This excerpt highlights how the accurate and intense attention involved in care presupposes a sort of managerial standpoint. In a tense situation where an accident may cause immediate death, Ms. F. speaks as a manager, from a detached point of view; this is probably because she can handle such situations without difficulty if she herself is beside the bed. However, she worries about her young

staffs' practice. The word *yappari* describes, always but implicitly, the circumstances of caring for an ALS patient; Ms. F. chooses it to convey the particular nature of the care.

Something always happens. However, we must avoid a fatal accident. Such predicament gives ALS care a special intensity. The role of the caregiver entails preventing the actualization of a possibly fatal incident. This is why a caregiver must not allow the phrase, "I do not know." ALS requires an absolute comprehension of the patient's body and intentions. The caregiver's preparedness encompasses the risk of death during daily care.

It is interesting that, given the ever-present risk of a fatal accident, Ms. F. insists on the autonomy of each staff member. Nobody can give up their practice in the midst of caretaking by saying "I do not know;" they must do what they consider is right. The ALS condition implicitly suggested by the adverb "*yappari*" requires the continuity of care and determines the "style" of practice in each situation. We borrow the concept of "style" from Merleau-Ponty [15]. The style is the matrix on the basis of which various creative practices can be carried out; it gives coherence to each action, despite the latter's variety. Style, then, is nothing but the expression of subjectivity insofar as it shapes the encounter with and the response to the complexity of each individual's situation.

## The Continuity of Communication

### Reading the True Meaning

Overcoming the time lag involved in communicating with the patients is a necessary component of care.

Researcher: It [caring for a locked-in person] is very different [from the care of the elderly person].

Yes, totally different. . . . In the care of the person who cannot speak, we try to read the true meaning through very few words. It requires not only experience, but also skill. There are caregivers who are capable and those who are not.

Researcher: Ah, so is it.

Ms. F.: Yes. The capacity to read the true meaning of our patients is a very important element of this profession. The patients become more and more unable to articulate and finally they lose their

voice when they start to use the ventilator. First they can speak normally and the pronunciation becomes "*dondondondon* [rapidly]" inarticulate. They try to convey what is in their mind of course [*yappari*] with very few words. In this condition, we must have the willingness to read, "What does he want to say?" It is not enough if we do nothing but the care ordered by doctors." (13)

In the last paragraph, Ms. F. was interested in the sustainability of the patient's life. The ability to understand the patient's words and the continuity of communication become the central topic. Here we learn about communication not in circumstances of machine trouble, but in daily life. The adverb "*yappari*" (because, of course, etc.) introduces the dialectic between the discontinuity of communication due to the handicap and the continuity assured by the caregiver and the technology. It implicitly describes the ALS condition as it determines the caregivers' practice.

Ms. F. often used the word "true meaning" (*shin-i*), which is not very frequent in Japanese. The "true meaning" derives from the very nature of ALS. It is difficult to grasp what the patient really thinks, and Ms. F. has to find the "true meaning" that is hidden behind the pronounced signs. The ability to understand it therefore serves as a filter that selects qualified caregivers. In this way, ALS and the technology that assists the patient strongly determine the caregiver's style.

When a patient is locked-in, the "true meaning" always differs from what the patients actually said with the spell board. What they really want is more than what they actually say. "First, they can speak normally and the pronunciation becomes rapidly inarticulate, and they try to convey what is in their mind of course a [*yappari*] with very few words." The caregivers' imagination, which rests on the historicity of care, must fill in the communication gap. "Historicity" is used here to designate the fact that care is a relationship that exists in time and sustains the caregiver's understanding of the situation. Imagination, then, operates as an experientially-based function that helps overcome the time lag and the risks involved in the communication gap. The care of the ALS patient aims at insuring the continuity of communication, which is always at the risk of disruption.

### Historicity in the Alphabet Board

We are not speaking only the time lag that occurs at every moment of communication. Slow



communication with an alphabet board results from the gradual weakening of communicative possibilities and the concomitant reciprocal effort to communicate – a situation that will persist even with the use of brain computer interfaces. Adequate communication with a spell board presupposes the existence of previous communicative situations, and at the same time reflects the rhythm of its own weakening. The caregiver's capacity to read the patient's true intended meaning is based on this historicity.

Ms. F.: A young patient who declines very fast loses *dondon* [rapidly] the mimic of the face. Indeed, he cannot smile even when he wants to smile. Nevertheless, there is someone who inconsiderately says, "he sleeps?" [and I reply to him] "No! He is awake!" I think, "Why does she say such an insensitive thing?" The mode of communication changes *dondondondon* [rapidly]. I really think, "It is cruel at this young age." That is why I am concerned about the extent to which I can really assist them. And when I can read their words, I bless myself.

Researcher: Ah, I understand.

Ms. F.: My relationship with him goes back to the period when he was active and could speak [i.e., here, Ms. F. started to remember a patient who recently died]. I understood his personality. He was very modest... And I would like to offer something joyful even in this actual condition [in LIS]. (38)

The onomatopoeia *dondondondon* (rapidly) qualifies successively "articulation of the pronunciation", "mimic of the face" and "mode of communication." The patient simultaneously loses verbal and non-verbal communication. The caregiver and the patient try to create a new mode of communication in this condition, and this new mode is based on their mutual experience, gained when the patient could still mimic. The fact that Ms. F. can praise herself and feel relieved when she achieves successful communication with her client is enabled by their long relationship. Both the ability and the will to read the patient's sign reflect their common history.

## The Difficulty of Communication

By virtue of the challenges it raises, communication now becomes an ethical issue in itself.

Ms. F.: For example, when I continue to stand beside the bed and try to read what my client wants to say for three or four hours, in fact I ask myself, "What am I doing now?" Even though I read some letters, and sometimes these letters do not mean anything . . . Reading the letters, [I ask myself] "What am I doing?" . . . Really, I disappoint myself with a feeling of inability and ask myself "What really am I doing now?" . . . When I can read a meaningful word, I bless myself. I become very happy when I can read what he/she wants to say. (19–20)

In this excerpt, the repeated monologue "What am I doing?" contrasts with "I praise myself." This reflects the extreme situation where it is difficult to decipher the other person's signs.

When we described the accident related to the ventilator, the rhythm of the scene was very rapid. The caregiver was hurried by the risk of death. In contrast, rhythm in daily communication is very slow: Ms. F. reports, "I take sometimes three hours to read ten letters" (21). More precisely, there is a disparity between the rhythm of the pronunciation (three hours for ten letters) and the rhythm of Ms. F.'s thought, as expressed in the repeated "What am I doing?" The "conversation" is in fact dominated by Ms. F.'s monologue. It is as if the monologue were part of the communication.

Nevertheless, even if Ms. F. cannot understand a word, even if she stands during those three hours besides the bed in vain, those hours without transmission *are* the communication. The patient tries to tell his or her mind and Ms. F. strives to understand it even when it is hopeless. Thus arises something like a naked communication, a pure "form" of communication without contents. That is why Ms. F.'s monologue can be considered as a part of communicating with the patient.

We can now understand the particular rhythm of the care of ALS patients. On the one hand, the caregiver has to watch the patient through eight hours without interruption. On the other hand, it takes three hours to understand ten letters. These two rhythms are heterogeneous. A particular polyrhythm thus makes up the daily life of the persons who suffer from ALS.

Communication in such circumstances is very difficult; however, it is not impossible, and Ms. F. says, “I must not give up!” (21), even when she cannot figure out the letter the patient intends to express. The communicative imperative becomes obvious at the limit of the possibility of communicating, as paradoxically proven by the caregiver’s monologue substituting for dialogue.

The following excerpt depicts from the outside the scene of the internal monologue:

Ms. F: He could no longer easily move the eyeballs. And he could not intentionally move the eyelids. The caregiver opened his eyelids partly and showed him the alphabet board. She gave him a choice between, for example, “A” or “B” and read a slight movement of the eyeballs that indicated “yes” or “no.”

He could not move the eyeballs easily, and we had to ask the same question many times “A” or “B”. “Mmm, I cannot read. Try it again!” We continued endlessly. . . . It takes really three hours to read ten alphabets. However, despite our effort, it often becomes an incomprehensible word. Or sometimes, we understand what the patient wants to communicate. If we cannot read, “Sincerely, I am very sorry....” It is extremely tough; however, we must not give up.” (20)

Here, communication is always on the edge. When one tries to read ten letters every three hours, each second of those hours constitutes communication. The interview depicts Ms. F.’s monologue, but the monologue implies a potential exchange where two interlocutors try to communicate with each other for three hours. That is why the monologue embodies the contact between the patient and the caregiver in the form of a naked communication that anticipates or stands for verbal interaction. As the last excerpt indicates, Ms. F.’s monologue implies intersubjectivity, and to that extent, it is *indeed* the communication itself.

Reading ten letters in three hours constitutes a special rhythm that many of us cannot experience in our daily lives. This rhythm is also different from that of the continuity and the intensity of the constant vigilance the ventilator requires. The care of the ALS patient involves handling these two strange temporal rhythms.

In short, communication is extremely difficult; yet it is not impossible. It requires the caregiver’s effort – as

Ms. F. says, “We must not give up.” Note that Ms. F. emphasizes “We must not give up” just when two-way communication becomes impossible. This paradox highlights the communicative effort as an irreplaceable value of human beings.

### **With the Vital Signs Monitor: Final Achievement of the patient’s and the caregiver’s Subjectivity**

#### **The Continuity of the Environment and the Individuation of the User**

Even when the situation becomes extremely difficult to endure, for example, when the patient is totally locked-in, their wish remains intact, and its realization becomes one of the caretaker’s central tasks. Ms. F. said, “Some of them [clients] are very nervous about the care that they receive and some of them do not care about that. [...] Each client is so different that I have to understand each need” (14). The effort to understand the “true meaning” implies understanding the client’s individual wish. In this task, the caregiver’s imagination is not arbitrary.

Ms. F.: For example, though I return [*kichinto*] things attentively to the appropriate place, sometimes I found in one house that one of my colleagues did not clean up or arranged the room differently. In such a case, I do not return the things without saying anything, but first I ask my client, “I found it here. You let it be there? Can I return it to the box?” I ask [my client] and anticipate [what he or she wants] and come back [*sakimawari shite kuru*] [to the actual condition]. I use my imagination and ask the patient many things.

Researcher: Okay. However, you do not merely use your imagination but you need the patient’s confirmation.

Ms. F.: Yes, I always ask my client. The patients want to attentively [*kichinto*] keep the things in place in the same manner. However, every caregiver is different and one can forget something, or another is not so neat. That is why we have to arrange and attentively [*kichinto*] keep the situation as attentively [*kichinto*] as the client wishes, and not to let them feel stress. (14–15)

The main subject in the excerpt is the continuity of the environment. And to maintain such continuity, the

caregiver's imagination and the patient's confirmation are both required. By repeatedly checking what her client wishes, Ms. F. confirms the validity of what she imagines. The starting point is the desire of the client who wishes to keep the room neat. Here again, the caregiver's monologue (imagination) is bound with intersubjectivity. Ms. F. imagines and anticipates the ideal state based on her past experience, and checks the current environment. This explains her use of the circular expression "anticipate and come back to [the present situation]."

It is not only the patient's individuality, but also the caregiver's that define the particular character of a situation. When one caregiver replaces another, he or she rectifies what their colleague did, thus collectively maintaining the continuity of care. The patient's subjectivity is based on the caregivers' imaginative capacities and teamwork.

Ms. F. said, "We have to arrange and attentively [*kichinto*] keep the situation attentively [*kichinto*] always as the client wishes." She uses the adverb "attentively" [*kichinto*] repeatedly (it appeared in the first excerpt we provided: "I attentively monitor all the moments during the stay... Our care really requires attentive observation"). "Attentively" signals the place where the ethic of care operates, and it is used for the continuity of life and the environment in a situation where both are constantly in danger.

#### Order of Priority of the Wishes: How to Realize Subjectivity

Paradoxically, the harder the communication becomes, the more the patient's singularity asserts itself. When a patient is paralyzed, they achieve subjectivity along the lines of their wishes.

Ms. F.: If the rhythm [of the patient's weakening or deterioration] is rapid, the patient rapidly loses communication, even when they are young. In such a case, the caregivers must understand the order of priority and we [caregivers] address the words anticipating [their wish].

Researcher: It sounds difficult to me.

Ms. F.: Hmm, yes. We feel in our daily care "He likes such a thing!" and we discuss this in our meetings. We feel together, and decide, "We will

care for him in such manner." Of course [*yappari*], each caregiver feels a different thing; however, [we discuss and agree]: "Ah, however there is one common thing among these things that we see" and "In such a situation, for example, this client's primal concern is..." and we try to feel together and afterward we agree on the trivial things. (18)

When communication becomes difficult, the caregivers try to understand the patient's primal concern and wish based on their past experience. Patients realize their subjectivity through their wishes. However, because this depends on the caregiver's imagination, the patient's subjectivity also materializes by way of someone else's imagination and the discussion of the caring team. This team is constituted as the caregivers seek to fulfill the patient's wishes. Thus, the patient's individual subjectivity is in fact the collective affair of the patient and the caregivers together. Furthermore, such collective subjectivity happens at the rhythm of the patient's weakening. Paradoxically, then subjectivity is realized as a result of the illness.

Ms. F. gives the example of a client whose favorite hobby is enjoying the concerts of a rock band. She reserves a seat when she finds information about the concerts and accompanies him to the concert hall. The patient's subjectivity through his own wish becomes more apparent when his body is paralyzed; the client in question uses the ventilator and cannot speak. The rhythm of deterioration generates a parallel movement whereby understanding and fulfilling the patient's wish becomes increasingly dependent on the past experience of care.

Making the patient's wish happen becomes the wish of the caregiver; his subjectivity implies the caregiver's. In turn, the caregiver accomplishes her or his subjectivity by becoming someone who ensures the continuity of the patient's life and someone whose wish resides in the realization of the patient's wish.

#### Subjectivity in the Total Locked-in Syndrome

In the last part of this article, I would like to describe the care of the patient in the total locked-in syndrome (TLIS).

Ms. F.: Yes, it is different [from palliative care at home of patient with cancer]. We continuously



watch out...; however, [the situation would be different] if the patient could explain how they would like to spend their last days and how they would realize their wishes...If you are in TLIS, you say, "It is impossible, is it not?" What we can do for his or her family is to show our care: "We watch him carefully" . . . .

Our visit in the last days is different [from the daily care in the chronic phase]. We can judge the state only by the vital signs or the color of the face [because there is no expression], and we observe attentively. (30)

In the excerpts quoted in the previous section, Ms. F. often uses the prefix *kô*, when she talks about patients' small wishes. In this last quotation, however, she did not employ it. The difference of style denotes a qualitative difference between the care during the chronic phase and the care during the terminal and total locked-in phase. Nevertheless, the next quotation shows that communication in the locked-in state is based on the relationship established during the chronic phase.

Ms. F.: Even when our client is totally locked-in, if we already knew, for example, [*kô*] in advance that he is fond of walks, we call him and say, "Let us take a walk!" and went out, for example, [*kô*] for one hour or so. [Here, Ms. F. started to use the past tense; she was reminded of the abovementioned patient who died recently.]

Of course, the family – the client was the father – wished, "He likes to go out. Please let him feel the air outside." And we went out. They wished, "Please continue the daily life as he spent it." (26)

Before this excerpt, Ms. F. described the daily life of this patient before the locked-in syndrome. When she first visited him, her care was centered on supporting his social relationships by, for example, sending emails for him. However, as the patient weakened, care became more focused on health control through monitoring vital signs (25). When he entered TLIS and was deprived of all communication abilities, Ms. F. walked around with him laying in bed. It is as if the care of ALS patients has finally returned to sociality in TLIS. The family and the caregivers try to understand the client's wishes and to realize them (that is why the prefix *kô* is used). The care provided in the locked-in phase is based on the

accumulation of readings of the patient's wishes during the chronic period – in others words, on the historicity of care.

All this implies that we should not treat the locked-in syndrome separately from care and its historicity. Life in LIS is shaped by the relationship and the care lived during the chronic phase. When the body is totally immobilized and communication becomes absolutely impossible, the accumulated experience of past communication is used to care for the patient. Describing care in the chronic phase, Ms. F. uses a lot of inner dialogue in place of actual conversations. Then, in the terminal phase of LIS, this inner dialogue turns into the only possible real conversation. Ms. F. says naturally, "Let us take a walk!" to the patient who cannot reply to her. Because the patient is now completely silent, it is the caregiver who actualizes and activates the dialogue. Her words embody at the same time the actualization of the inner dialogue in the past (which replaced actual conversations) and the preservation of the relationship even after the patient has become totally locked-in.

Thus, the patient and his or her caregivers achieve their subjectivity together. The caregivers' practice accomplishes the patient's wish, but together they form a singular community of desire that individualizes itself as such.

## Conclusion

ALS patients require a particular technique and awareness on the part of caregivers. In Japan, the social initiative of the patients themselves led to a high level of support and to the institutionalization of home-based care with a ventilator. Because of those circumstances, a particular style of care developed in Japan, which is hardly comparable with the care of ALS patients in other countries. Such care greatly improves the quality of life of patients who must use a ventilator. As mentioned, professional caretakers, who have acquired special skills for ALS-compliant care, are not affected by despair or anxiety, as is often the case with family caregivers.

The intensity of observation and the time lag in communication characterize the intentionality of the caregiver who tends to the ventilated ALS patient. The difficulty to communicate requires a caregiver's sharp imagination and accumulated experience. When caregivers grasp a patient's needs and wishes, they can fit into the patient's world and help fashion it accordingly.

Through the teamwork of the caretakers who collectively realize a patient's wish, the patient accomplishes his or her personality and enjoys the established rights of persons with disabilities.

### Limitations

This study does not discuss the social and cultural conditions that enable and determine care. The view of personhood in Japan, where the Western type of individual autonomy does not have primary value, as well as the social system for supporting disabled people, enable life with ventilator in the patient's own home.

Each caregiver and each care team has their own style, and each patient is different. This article is a case report, or more precisely, a detailed analysis of one case. This is a limitation; however, as we have shown, one singular case already serves to demonstrate the complexity of care. Further phenomenological qualitative research with other cases could bring to light other aspects.

Ms. F.'s practice demonstrates how the care of ALS and LIS patients involve an intersubjective history. I would like to emphasize that her style illustrates a typical temporal structure, characterized by an intense rhythm in the care of a patient with a ventilator and an extreme slowness of communication, which is determined by the condition of ALS patients in general. Thus, even though the caregiver's style is individual, the way it operates characterizes typical circumstances, and what we have described in this article concerns universal issues and processes of ALS patient care.

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### Compliance with Ethical Standards

**Conflicts of Interest** The author does not have any potential conflict of interest to disclose.

**Research Involving Human Participants and/or Animals** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed Consent** Informed consent was obtained from all individual participants included in the study. The study was examined and approved by the ethics committee of the author's institution.

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