

Certainly enough, a patient's interpersonal relationships go beyond those with one's healthcare provider. Patients live and exist with their families as part of society. According to Kleinman, illness is not merely a personal experience; it is a mutual, communicative and, ultimately, a social experience (3). As described above, we surmise that similar to, or even more than, how the patient-health professional relationship has an impact on a patient's lifestyle, a patient's interpersonal relationships with his or her family and community – with which they spend the majority of their time – have a significant influence on patient's QOL and welfare. In particular, medical care for patients with obstinate diseases who are physically limited by their disease necessitate social welfare and constant family support. The quality of care for patients with obstinate diseases depends largely on a patient's interpersonal relationships as well as on other's attitudes and behavior. Accordingly, a survey study is needed on how patients with obstinate diseases maintain their relationships with family and society, and how patients' families and communities recognize and accept a patient's disease and disabilities.

Even today in the field of psychiatry, families of patients with depression hold a fixed idea that depression is “a disease of idleness” as a result of being unable to understand that depression is a disease which requires careful consideration of a patient's condition. Accordingly, this necessitates healthcare professionals to help patients' families in understanding the patient and his or her disease (4). There are also cases when a patient's family suffers directly from a patient's disease and becomes physically tired and emotionally unstable (3). As a result, a family's emotional and physical capacities to understand the patient's suffering are lost leading to possible breakdown of familial relations. Even within a patient's community, prejudice continues to exist against patients infected with HIV or Hansen's Disease (leprosy) (5). Relationships of prejudice perhaps inflict a great deal of emotional and social harm on the discriminated persons.

In Japan, as far as we know, there exist neither studies on how patients with chronic obstinate diseases perceive their personal and social interpersonal relationships nor on the types of problems patient face in those interpersonal relationships. We believe that an understanding of how patients perceive their relationships will allow us to reveal part of the problems inherent to these relationships and propose a possible way of dealing with these problems from a medical perspective. Accordingly, this study's objective is to reveal the problems that patients with obstinate diseases face in their interpersonal relationships. Based on our findings, we then consider the behavior, attitude and medical intervention that healthcare and healthcare-related professions should take regarding these problems.

METHODS

Between May and November, 2003, we conducted semi-structured interviews with outpatients of the Department of Neurology at the Mie University Hospital. A convenient sample was taken of

patients whom the attending physician (YN) judged to be physically capable of participating in an interview, whom were adults with decision-making capacity, whom could communicate effectively, and whom provided their informed consent to participate. Interviews were conducted in a room at an arranged time following the patient's check-up on a different floor than the Neurology ward.

Interview questions focused on the following items: lifestyle problems that the patient has faced as a result of his or her obstinate neurological disorder, the patient's family, local community, medical requests, and any problems at the time of medical decision making. Data on participants' age, sex, diagnosis, marital history, occupation and religion were collected at the time of the interview.

Interviews were conducted primarily by one investigator (AA). However, the attending physician (YN) had conducted interviews on two patients with Amyotrophic Lateral Sclerosis (ALS) in the medical examination room immediately following their medical appointments. In regards to these two patients, the attending physician judged that it would be too strenuous for these patients to participate in an interview separate from their medical appointments. An interview conducted by the attending physician was more appropriate on the following basis: one patient was male with advanced ALS who was physically disabled and had difficulty speaking; the other patient was female who had difficulty breathing and required written communication due to a tracheotomy. Upon obtaining informed consent, observation on patient interaction via audio tape was also conducted in order to compare with interview data. This was conducted by the attending physician who participated in this study (YN).

Observation and interview recordings were transcribed verbatim and analyzed using qualitative content analysis (6). This consisted of, first, selecting portions of the transcription that related to everyday interpersonal relationship problems and to the patients' perception of their family and other people, next, coding these portions and, lastly, creating categories based on the association between codes. The qualitative content analysis was initially conducted by three investigator (AA, YN, and EN). The remaining investigators reviewed these preliminary results to further verify reliability of findings. Research team discussions were also used to select interviewees' representative statements.

Content analysis validity was ensured by comparison of interview responses and observation recordings as well as by content analysis being conducted by multiple investigators. When we compared each patient's interview responses with the patient's utterances during his or her medical checkup, no incongruities were found regarding patient symptoms, limits of ADL, home environment, state of social welfare, primary complaints and other lifestyle problems. No differences existed in codes and categories created respectively by investigators. Given the sensitive issues related to interpersonal relationships, member checking interviews were not conducted with patients due to possible psychological harm. This study was approved by the Mie University School of Medicine Ethics Committee. All investigators have participated in the

conception and design of this study, discussed the accuracy of the lists of codes and categories, and joined the writing of the final version of the paper.

RESULTS

Interview Participants

A total of 12 patients among outpatients with obstinate neurological disorders were asked to participate. Ten patients provided their informed consent to participate in a semi-structured interview and to have the interview recorded. The two patients who chose not to participate were female with Parkinson Disease.

Table 1 shows participants' background. Our sample consisted of six males and four females ranging in age between 40 and 70 years old; all participants were living with their families. Six participants were Buddhist and one was Christian. Diseases included Parkinson Disease (PD, n=4), Amyotrophic Lateral Sclerosis (ALS) (n=3), myasthenia gravis (MG) (n=1) spinocerebellar ataxia (SCA) (n=1), and progressive supranuclear palsy (PSP) (n=1). In five of the interviews, patients were accompanied by their spouses (ALS (n=3), MG (n=1), and PSP (n=1)).

Findings are based on content analyses of interviews conducted with patients (n=10) who had provided their informed consent. This study focused on problems related to interpersonal relationship that patients with obstinate neurological disorders face. In our description of results presented below, codes are represented by single quotes, categories are represented by double quotes and excerpts from interviews are in *italics*.

Problems with interpersonal relationships with family members (household interpersonal problems)

1. "A lack of understanding from one's family"

Participants felt that their pain and suffering from disease was not sufficiently understood by their families. Patients felt that they were blamed for "faking being ill" in times of family conflict especially in cases of PD with fluctuation or when their family acted insensitively towards the physical constraints or failures brought about by their disease. That is, patients' families would 'behave bitterly' toward behavioral constraints or failures due to one's disease, and familial relationships would become complicated when patients were blamed for 'playing sick.' While we cannot say that this demonstrates a causal relationship, a fraction of participants felt that their disease had caused a great deal of stress for their family and, thus, had caused 'family strain.'

Dissatisfaction... I would probably say it lies in how much my family understands. I move around a lot and my family probably thinks that not much is wrong. Thus, I guess it is unlikely that my

family understands my position. (Male in his 50's, SCA).

In getting sick, all my worries are family-related. How can I say this? In becoming disabled like this, my family assumes that I brought my Parkinson Disease on myself (female in her 60's, PD).

2. "An inability to carry out one's role as a family member"

Obstinate neurological diseases make it difficult for patients to carry out their role as a family member. Interview participants could not play their 'role as one of the bread makers' or their 'role as the women in the family' and would consider themselves as 'a disturbance.' This caused many participants to feel 'a sense of inferiority' and/or to feel 'reserved' towards family members.

Being unemployed in itself. (Male in his 40's, ALS).

I can't clean or do my house chores as I please. Although my daughter in law does a lot of the chores and cleaning for me, I feel so reserved. (Female in her 70's, PD).

3. "A lack of family support"

Patients' needs were not always prioritized within the family. 'Family circumstances' were quite influential. For instance, remodeling one's home for easier movement was impossible because of a child's resistance to live at home together or adequate family support was not available when only husband and wife lived together due to one's child having grown-up and now living away from home. Other examples include families that have to deal with another family member being sick. Psychological harm as a result of 'awareness of male and female roles inside the house' also existed. Results described that in the case of female patients, husbands would not actively do the house chores.

I want my daughter who lives in Tokyo and has yet to marry to return home, but it is impossible to find work around here; she is a high school teacher and would have to retake the licensing examination. There are a lot of things to consider. (Male in his 60's, ALS)

There are times when I have to carry a small package or something, and I thought my husband would do it for me, but... with my mother in law around, he just won't do anything. Unlike the children today who would immediately take notice and offer to carry it for me, my husband will not do it even if I ask him. (50 year-old female, PD).

Problems related to interpersonal relationships with people outside of the family

4. “A lack of understanding from society”

Participants felt that, similar to their feelings toward their own family, society did not understand their pain and suffering brought about by their disease. Society is defined here as those interpersonal relationships outside of the family. Many participants suffered from people being ‘cold’ and ‘not understanding.’ They wished that people would ‘be kind’ and ‘be considerate.’ While no concrete examples were provided, many participants felt a sense of ‘discrimination, prejudice.’ Other patients felt the need to ‘personally explain’ one’s disease and raise people’s awareness since society ‘lacked awareness and understanding of disease’. Even though people did not see a patient’s symptoms to be severe enough to be fully recognized and to be treated kindly, symptoms were indeed quite painful for the patient him or herself.

*(Interviewer asks, “Do you have any requests towards your family or the people around you?”)
That would be to be kind. To be kind is my first wish. My grandchild already hates me. He sometimes says, “When grandma comes, we can’t do anything; you don’t need to come grandma.” My daughter in law does a great deal for me, but... even with her, I feel that I am a trouble. I feel that I am a bother. If I go out with them, they have to walk slowly and lag behind. No matter what I do, I always need other people’s help. (70 year-old female, PD).*

Ultimately I guess I want society to have some consideration for my disease... It would be hard to answer how to do this, but ultimately (in order to have people understand), one has to confess to be sick and get people to understand. (50 year-old male, SCA).

5. “Inability to participate in society”

The fact that patients could not perform the same tasks as a healthy individual – ‘we cannot do anything together’ – limited patients’ ability to participate in society. In regards to specific activities daily living (ADL), participants often felt distress because of their ‘inability to do something alone’ and the need ‘to tolerate’ having always to go places and do things with caregivers.

Even with walking, this does not work. So when walking, I bend all the way over. Unless I lean to the side, I can’t go forward. My physician says to stop walking for a little while when that happens and then to start walking again. So I stop for a little while and struggle walking with my cane while everyone just passes by and goes ahead. Why did I have to get sick like this... (60 year-old female, PD).

6. “The eye of others”

The inability to participate in society due to constraints on one’s everyday movements was

extremely stressful. However, having people watch one's each and every movement made it even more difficult to live with an obstinate neurological disorder. Participants would always 'feel conscientious of others' and 'different from other people.' For instance, when a patient would fall down in public, he or she would feel conscience of 'looking bad' while also worrying about physical harm. Participants would 'worry (feel concerned)' about 'being a trouble to others' and about one's bodily movements seeming 'unpleasant' to others. Similar to how participants felt towards their family members, many felt 'a sense of inferiority' in society. Even patients with myasthenia gravis who are free from most symptoms felt 'different from other people'.

If I were to fall while on a trip or out shopping, I think "oh, this looks bad" (Interviewer comments, "While, in fact, your body is much more important than looking bad"). "Looking bad" is also a consideration. (60 year-old female, PD).

Now, my lifestyle is very much like the lifestyle of a normal person. I try not to become tired. But when I do get tired, I either take a morning nap or an afternoon nap. When I am really busy, I am up all day, but... well, I try to lay down either in the morning or early afternoon. (40 year-old female, MG).

DISCUSSION

Findings highlighted that patients' disease and suffering are not understood fully by their families, that patients feel a lack of family support and cooperation, and that society's understanding of disease was also insufficient. Again, findings revealed that patients recognized their inability to perform personal activities and to behave satisfactorily within the contexts of family and society. Ultimately, this lowered their self evaluation.

Before we assess the above findings, we would like to confirm this study's limitations and problems. Firstly, the final sample consisted of ten patients. Although we used qualitative interviews in which sample size inherently does not affect study quality, our sample size was limited when compared to similar studies that have been conducted abroad. Accordingly, this study serves as a preliminary survey. Problems beyond the items referred to by interview participants may exist. Secondly, it is possible that the five patients who were accompanied by their spouses at the time of the interview were unable to express their honest opinion regarding their spouse's behavior and attitude. However, we were able to gain sufficient understanding of patients' feelings towards their families from patients who were not accompanied by their families. Thirdly, this study's sample consisted of patients with obstinate neurological disorders who were able to visit the hospital on their own or with additional help in order to receive outpatient care. Accordingly, it is possible that perceptions of interpersonal relationships differed among patients

whose disease was too advanced to receive outpatient care. It is also possible that perceptions of interpersonal relationships differed among patients with a non-neurological chronic obstinate disease. Lastly, and most importantly, results are ultimately based on patients' subjective perceptions and do not reflect the actual degree of understanding and support among patient families and society. Findings consist of "what patients feel" and "what patients think" and do not provide an objective account of what is actually occurring in a patient's surroundings. This study included neither interviews with patient families nor observation of what occurs outside the examination room, which could have substantiated patient's views. Accordingly, this study does not contain data analyzed from a third-person perspective on patient-family or patient-community relationships.

After considering these limitations and based on the items expressed by patients related to relationships with family, community and oneself, we would like to discuss the type of training healthcare professionals should receive and what can be done. There are several lessons that healthcare professionals should learn from this study's findings, but we have summarized these lessons in the following three needs: "the need for empathy," "the need for self esteem," and "the need for support." In light of the excessive literature on the need to support patients with obstinate neurological disease in the areas of social welfare, care giving, nursing and medicine, this report focuses on "the need for empathy," "the need for self esteem."

Certainly empathy is essential to interpersonal relationships. Perhaps all people have experienced the pain of "no one understands" or the happiness of "being understood." Even if one can not heal a patient's disease, a healthcare professional can ease a patient's suffering just by sharing their pain. Nevertheless, it is impossible to understand fully another person. In particular, it is extremely difficult to share the suffering of pain which one has never experienced. Suffering of disease is similar to QOL from the perspective that both depend on a patient's subjective perspective. The everyday pain of patients with obstinate diseases is immeasurable. It is even difficult for a patient's family to understand the feelings of patients whom live day-in and day-out with disease. Interpersonal relationships that are unable to provide and, thus, lack empathy are sources of pain.

Accordingly, health professionals need to ask themselves constantly, "Am I understanding the patient's suffering?" Vital questions include, "Am I able to stand in the other's shoes?" "Am I able to see things as the other does?" and "Am I interacting with consideration?" So the question remains as to how we can be empathetic human beings. Ethically speaking, this question can be restated as how we can acquire the virtue of "empathy." This report will not pursue this difficult query, but rather seeks to confirm the absolute need to maintain an empathetic demeanor in the context of patient care. Enrichment of medical education within this area is also desirable.

As Kleinman has pointed out, disease alters a patient's world and disease destroys patient

families (3). Maintaining healthy relationships is difficult inherently, but a patient's disease and the disabilities that accompany that disease further complicate that relationship. It is easy to imagine the difficulty for a family to understand a patient's suffering and fully empathize with that patient in a household where the familial relationship is dysfunctional. Likewise, we should not forget that it is difficult for healthcare professionals to understand the feelings of a family who is caring for such a patient. Under these circumstances, a healthcare professional is able to educate families on how to understand a patient's disease as well as able to support families who face physical, psychological and economic stress by living with the patient. Policies that promote caregiver support, consideration of burden, and improvement of caregiver QOL are important. For instance, given that physical constraints are inherent to several neurological diseases, it is necessary for healthcare professionals to explain to the family that, as a result of the disease, the patient's condition will worsen no matter how hard he or she tries in rehabilitation and that regardless of a treatment's quality, the patient's prognosis will remain poor. It is also valuable to inform families of social resources such as caregivers and social welfare. Likewise, we believe that it is important for healthcare professionals to be empathetic towards the suffering that a patient's family experiences. However, further exploration is needed on whether health professional can and, if so, how far they should intervene in family problems which, ultimately, are private – except domestic abuse to the patient.

In regards to a lack of understanding in one's community, we recognize that discrimination and outright disregard derives from ignorance and illogical hate. This highlights the importance of further spreading the concepts of human rights and promoting general education on disabilities and medical care. However, a societal lack of understanding for disabilities and disease cannot be cured by medical care alone. A change in behavior toward society's weak is needed.

This study revealed that patients severely lose self-esteem. Patients feel ashamed as a result of not being able to fulfill their roles, which consequently instills feelings of self-insufficiency and makes patients conscientious of others. Feelings of inferiority also arrive as a result of not being able to participate in society. That is, this can be summarized by a self-image of I am 'abnormal and unworthy.' Kleinman described that it is an indispensable necessity for healthcare providers to be highly sensitive to stigma and feelings of shame (3). Healthcare professionals should consider how to preserve a patient's self-esteem in the contexts of a patient-healthcare professional relationship and a medical care approach. Healthcare professionals cannot forget that imprudent behavior and communication can easily hurt a patient. Medical care is merely not providing benefits to patients. Rather medical care is based on "never causing injury" and "never harming." Therefore, medical education on the modality of the patient-healthcare professional relationship and on the fulfillment of professional ethics is indispensable.

The ultimate question, however, is what can healthcare professionals do in regards to the sense of shame and inferiority felt by patients with obstinate disease in their private and social lives? Unquestionably, this challenge is quite difficult to meet with only a medical approach. Today in Japan, there are currently no effective policies to eradicate a patient's self-perception of being 'abnormal and unworthy.' But, if patients, their families and friends, healthcare professionals and the community fundamentally change their standards of self-evaluation and the significance of and value in human existence, this social state may improve. Hence, a first step to recovering patients' loss of self-esteem could be found in a societal sharing of awareness. This awareness would recognize that the significance of and value in human existence can be determined not by being able to do something but in ways which maintain a patient's human dignity, that the concept of normality itself is strictly illusory, that one needs neither to be identical with another nor to be self-conscious, that, regardless of differences among individuals, a person can not live without the support of one's community and others, and, accordingly, that one does not need to lower themselves just because they receive support from family and community.

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Table 1 Interview Participants' background

Sex	Female	6
	Male	4
Age (range)	40 to 70	
Diagnosis	Parkinson disease	4
	amyotrophic lateral sclerosis	3
	myasthenia gravis	1
	spinocerebellar ataxia	1
	progressive supranuclear palsy	1
Religion	Buddhist	6
	Christian	1
	None	3
Living with their families		10