Caring for the Chronic Illness Patient of the Uncertainty －Simulated Experience of Body Immobility－

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要旨

慢性疾患患者の療養生活においては、仕事の継続困難や人間関係の崩れなど失うものが大きく、看護の視点は治療から患者のもつ不確かさへとシフトしている。本研究では、金正の示した身体不動性患者の病気体験の不確かさを参考に学生の擬似体験後の質問紙調査とレポート分析を行った。擬似体験は「コントロール感覚を取り戻せない」「他者に表出する気持ちの減退」という直接的な不確かさは体験可能だが、「今の生活状態でいることの揺らぎ」「生を問う手応えのなさ」という長期療養生活における体験は困難であることが明らかとなった。身体不動性患者のケアは、患者の状態の支援など精神的なものや残存機能に着目することなど多く学んでいた。患者の持つ不確かさを慢性期看護に活かすためには，疾患に限定することなく症状を中心とした擬似体験も必要である。

キーワード：Simulated Experience、Uncertainty、Chronic Illness

Introduction

Although life extension in nervous amyotrophic lateral sclerosis (hereafter, ALS) has now been obtained due to advances in medical equipment, the problems it causes are immeasurable—difficulty in holding a job, loss of social standing, collapse of human relations, and so on[1]. From the nursing aspect too, the focus is shifting from medical treatment to the uncertainty which a patient experiences during long-term nursing.

To help the patient understand their own difficulties, and as a way of teaching students about chronic illness at university of nursing, students are encouraged to have contact with chronic ALS patients and take part in simulations[2]. We have been using simulations since 3 years ago in their lectures about nervous diseases in the context of nursing chronic illness [3]. This study, by giving students a "body immobilization simulation experience" aims to help to (1) promote learning from simulated experiences in nursing education, and (2) promote understanding of uncertainty in ALS patients.

Methods

1. Definition of terms <Uncertainty of ALS patient>

In the nursing of chronic illness in Japan, attention has focused on the instability and uncertainty of patients or their health care providers as to how to go on living, and particularly on the patients' "uncertainty."

Yamanishi, Nogawa et al, from Mishel's definition, interpreted it as a "vagueness about the disease state," (Yamanishi) or a "state where there is no clear meaning about various things connected with the disease." (Nogawa) The common feature here is not only "a state of uncertainty," but also the fact that it is difficult to attach a meaning to it, or to identify it[4-6].

Kinsyo stated that in these diseases, "an uncertainty is an unbalanced cognitive state in which it is difficult to understand the situation, to give it meaning or to evaluate it," "non-equilibrium state arises where it is difficult to understand the situation, to give it meaning or to evaluate it." [7,8] We used Kinsyo's definition in this study.

2. Subjects

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63 third year nursing students of A University. Candidate students had just finished their first 2 week nursing practice at the end of sophomore year . Although they had completed courses on dissection physiology, fundamental nursing, and the concept of adult nursing, they had had no lectures about the chronic illness . In nursing practice, about 10 students who had completed their nursing practice took charge of patients who could not move.

3. Study methods:

1) The Procedure of the simulated experience

In lectures on nervous diseases in adult nursing, students experienced a simulation of immobility experience at home, and were instructed to summarize their feelings on one sheet of A4 paper. In this immobility experience, students described ① imagining a serious nervous disease patient (body immobility patient) and ② staying completely immobile for 30 minutes at home.

2) Questionnaires:

In order that the questionnaire might show clearly how much a student has experienced the uncertainty of an ALS patient, a questionnaire study based on the uncertainty of ALS patients according to Kinsyo (30items, 9categories) was conducted with Kinsyo's consent. Questionnaires were retained for one month, and then put into envelopes and submitted. The questions asked candidates to classify their experience on four levels, i.e., "I strongly experienced it," "I experienced it a bit," "I didn't really feel much," and "I didn't feel anything at all," and were assigned points on a scale of 4 to 1[9].

3) Free reports:

We asked to the students to make a report to describe how they felt and what they thought about nursing at that time what they did and how they had changed since their illness, how they felt at that time.

4) Analysis

(1) Questionnaires: The average number of points in each category were computed.

(2) Reports: Student opinions were elicited by summarizing sentences which appeared to discuss uncertainty and nursing from the viewpoint of personal experience, in a single sentence. Common details in extracted sentences were summarized, and categorized. This categorization showed the definition of the concept behind the data, and was continued until there was agreement between researchers as to the definition and data content.

5) Ethical considerations

Participants were instructed to submit data so that the research objectives and individuals could not be identified, and analysis results were returned in such a form that individuals could not be identified during lectures. Moreover, it was explained in writing and orally that whether participants gave their consent or not, it would not adversely affect their academic performance, and that they were free to refuse participation. By submitting the questionnaire, participants were assumed to give their consent.

Results

56 participants (81%) completed this study. 8 participants was excluded from data analysis because of incomplete form .

1. Uncertainty with the Simulated Experience of Body Immobility (Table 1, Table2)

Table 1 Uncertainty with the Simulated Experience of Body Immobility (n=48)

Kinsyo's Category	Mean (SD)
Difficulty regaining self-control	2.83 (1.10)
Reluctance to express one's feeling to others	2.78 (0.97)
Difficulty getting used to the condition	2.38 (0.84)
Anxiety about the course of the illness	2.35 (0.53)
Unwillingness to involve the family	2.30 (0.87)
Perception of fading familial relations	2.29 (0.74)
Stoppage in thinking about pending arrangements	2.27 (0.83)
Fluctuating perception of the present life	2.21 (1.02)
Meaninglessness in asking about life	2.03 (0.65)

There was not such a large difference in the average number of points in the 9 categories (Table1). [difficulty regaining self control (2.83 ± 1.10)]

Table2　Uncertainty Experienced Due to Immobilization Experience (n=48,　352 items)

Kinsyo's Category(items)	Subcategory by Student's Report
Difficulty getting used to the condition(129)	Frustration
	Pain
	Itching
	Lassitude
	Distastefully
	Unpleasantness by sticking in the throat of phlegm
	Negative idea
	Defies description.
	Unimaginable
Difficulty regaining self-control(90)	Loss of feeling
	Inconvenience
	Alerting
	No control over time and space
Fluctuating perception of the present life(33)	Fear
	Troubled
	Limits of one's spirit
Stoppage in thinking about pending arrangements(16)	Hopelessness
	Anxietas
Anxiety about the course of the illness(3)	Thinks about only one's condition
	Expectation for the medical treatment
	State of unknown future
Reluctance to express one's feeling to others(30)	Painful by shame
	Feelings of loneliness
	Decrease in communications skills
	Reluctance to express one's feeling to others
Unwillingness to involve the family(26)	Apologizing
	Human contact
	Crappiness
Meaninglessness in asking about life(25)	Think about the death
	Living again
	Painful that cannot be endured
	Decrease in sense of values
	Loss of sense of value

and [reluctance to express one's feelings to others (2.78 ± 0.97)] were higher score than other cotegories. And the lowest score was [meaninglessness in asking about life (2.03 ± 0.65)].

Student's report was classified by Kinsyo's category (Table 2).

1）[Difficulty in getting used to the condition] accounted for 9 sub-categories. This included negative feelings, <frustration> that I can't do the things I used to do, and a <lassitude > or <distastefully> due to the fact I cannot move.

2）[Difficulty regaining self-control] accounted for 4 sub-categories. [Difficulty regaining self-control] included <loss of feeling> due to persistent inability to move, or <inconvenience>. It also included <no control over time and space>, i.e., I'm worried about time, but there's nothing I can do about it.

3）[Fluctuating perception of the present life] accounted for 3 sub-categories. <limits of one's spirit>, which is the limit of tolerance to the condition, and <fear>, i.e., an irreversible fear, were extracted.

4）[Stoppage in thinking about pending arrangements] accounted for 2 sub-categories. It included a feeling of <hopelessness> and <anxiety> due to the irreversibility of the situation.

5）[Anxiety about the course of the illness] accounted for 3sub-categories.

6）[Reluctance to express one's feeling to others], which accounted for 4 sub-categories. It included experiences such as <painful by shame> since I can't do anything alone, <feeling of loneliness> because of loss of communication, and <reluctance to express one's feeling to other's>.

7）[Unwillingness to involve the family], which accounted for 3 sub-categories. [Unwillingness to involve the family]—since this was a simulation experience and it was difficult to experience passing time with the family, it was extended to others in addition to the family. When respondents reported their relations with others and their feelings about them, the reports included <apologizing> since I can no longer do anything myself, <human contact> because I want people around, and <feelings of low self-worth> due to changing relations since I can't do anything myself.

8）[Fluctuating perception of the present life] were no reports.

9）[Meaninglessness in asking about life] included 5 sub-categories such as <living again> after reconsidering life and death during the simulation experience, <Painful that cannot be endured > which describes the hardship not of life, but of the present condition, and <loss of sense of value>, signifying a loss of self-esteem due to the inability to move.

2. Caring for the body immobility patient

From their simulation experience, students classified nursing of the uncertainty state into four categories, 256 codes.

These were subdivided into 4 categories which was [quality of nursing staff], [support and strengthening], [assistance with daily life], [specialization and the nurse's role](Table3).

1) [Quality of nursing staff]

This category was the most extracted from the reports.

Table3 Caring for the Body Immobility Patient (n=48, 256codes)

Category	Subcategory	Code
Quality of nursing staff (61)	Attitude	Adopt an attitude which touches the patient. (Attitude)
	Attention to detail	Be wired in
	Positive thinking	Provide the better
	Dignity	We have to be patient's dignity
Support and strengthening (93)	Reliance	Build up a confidential relationship so that patients even talk about the little things.
	Sense of security	Be around by(be in one's side)
	Sense of stability	Attentive hearing and say something for the patient
	Change	Turn patient's life around for a change
	Comfort	Feel with time or changes of the seasons
	Mental support	Touch a supportive attitude
	Confirmation of purpose	Planning with patient the way to the best suited communication
	The importance of family support	Care with all patient's family
Assistance with daily life (70)	Change of posture	Since pain was felt even after 30 minutes, it is important to change posture repeatedly. (Change of posture)
	Preparing the environment	Help in the early detection
	Improving residual functions	Understand and support patient's position
	Assistance with daily life	Preserve residual function
Specialization and the nurse's role (32)	Information	Information about medical and care for the patient and family
	Helping patients change their lives	Felt it was necessary to make the patient's daily life richer, i.e., find another way for the patient to live, and find out what he wants to do.
	Ability	Predictive action
	Worry over unforeseeable uncertainties	Stand patient's peripheral vision

It is important to adopt an attitude which touches the patient. (Attitude)

Although <attitude> was not discussed in detail, this refers to the nurses attitude after having had an immobilization experience, and included <attitude>, <attention to detail>, <positive thinking>, and <dignity>.

2) [Support and strengthening]

This meant supporting the patient's uncertainty, and the support and strengthening which even an ordinary nurse can give.

It is important to build up a confidential relationship so that patients even talk about the little things.

These included <reliance>, <sense of security>, <sense of stability>, <change>, <comfort>, <mental support>, <confirmation of purpose>, and <the importance of family support>.

3) [Assistance with daily life]

This is the category which deals with specific nursing assistance.

Since pain was felt even after 30 minutes, it is important to change the posture repeatedly. (Change of posture)

This included <change of posture> which the candidates themselves felt to be necessary by the immobilization experience, <assistance with daily life>, <preparing the environment> and <improving residual functions>.

4) [Specialization and the nurse's role]

The difference from assistance with daily life is care which goes beyond such assistance, and care aimed at improving the quality of life. This category shows what is possible as part of the nurse's specialization.

The respondents felt it was necessary to make the patient's daily life richer, i.e., find another way for the patient to live, and find out what he/she wants to do.

This included <information>, which is more important for patients who have become immobile and are uncertain about their future, <helping patients change their lives>, <ability>, and <worry over unforeseeable uncertainties>.

Discussion

1. Uncertainty experienced due to immobilization experience

On this occasion, a large variation of points was not seen in the various categories. We think that the fact that there was a 30 minute time restriction shows the limitation of an experience which cannot be called, a patient experience. Character-

istically, students reported physical sensations, and hardship due to the obstacles. The immobilization experience provided a direct understanding of the age and illness of the patient.

On this occasion, [difficulty regaining self-control] and [reluctance to express one's feelings to others] achieved a high point score.

This was also the most discussed category in the report.

During the simulation experience, students reported <frustration>, <distastefullness>, <loss of feeling>, and <inconvenience>.

These can be learnt from the simulation experience of hardship due to the disease, so they were the easiest to experience in the uncertainty of immobilization experience[10].

Since most of the candidate students on this occasion had never met a chronic illness patient, as they had just finished the basic two-week nurses training course about two months before the simulation experience, and since they had gained some knowledge about chronic illness and nursing through the lectures, one can say that, even after 30 minutes, they were able to broaden their viewpoint of physical and spiritual hardship outside the classroom.

On the other hand, regarding [the meaninglessness in asking about life], the future and involving the family, the number of points was low.

In the reports also, concerning [the meaninglessness in asking about life], the responses included <living again> after re-thinking life and death during the simulation experience, < Pain that cannot be endured> which describes the hardship not of life, but of their present condition, and <loss of sense of value>, signifying a loss of self-esteem due to the inability to move.

Since these uncertain states needed a long-term viewpoint, it was difficult to comprehend them from a 30 minute immobilization experience. This suggested the need for some means during the lectures to allow students not only to experience physical hardship, but also to think from a long-term viewpoint[11].

There is some mention of "simulation experiences" during nursing training. Although it is impossible to replicate all patient experiences vicariously, it is possible to harness simulation experiences in one's own nursing practice. It is stated that because the simulation experience is effective even for only 5 minutes, and because the simulation experience takes place during everyday life, it gives us an opportunity to think about specific assistance measures[12]. This was not only a simulation experience, but an opportunity for nursing students to learn how to make a direct experience a part of their reflective experience[13]. From the reports collected after the simulation experience, it emerged that although there were some students who were able to gain some reflective experience, there were others for whom this was only a direct experience and nothing more. Although this was mentioned briefly in the lectures, one way of having students gain reflective experience is by getting them to write down their impressions on paper, while at the same time seeing others who have had a similar experience and hearing their opinions, which is what we did on this occasion.

2. The nursing to the uncertainty

In the nursing of uncertain states due to immobilization experience, most students replied that their role was not to focus on uncertainty, but to provide general <support and strengthening>, <high-quality nursing> and <assistance with daily life>. This experience is accompanied by hardship, and offered an opportunity to learn how to palliate it, but the simulation experience alone is limited in its ability to address more specialized issues.

In the science of nursing education, attention is given to nursing achievements at university and graduation, but the need for an education with more humanity has also been described[14].

If only specialization is considered, making a place for humanity is difficult, but addressing student feelings would be one way of achieving it.

In this research, when questionnaires were

distributed simultaneously, there were some terms to which a response had not been received. However, when compared with preceding research, even if the terminology was different, the students' learning was the same.

As to when simulation experiences will be introduced again, we have discussed this in the context of problems in the report after experience learning, and the matter of linking them to hands-on training. The introduction of on-the-job training has been mentioned in previous research, but it is also effective to introduce these ideas early on from the objective of a long-term standpoint[15].

References

1) Hiroko Muraoka : Discovery of a Process of Search for the Meaning of the Illness in Patients with Amyotrophic Lateral Sclerosis. J. Jpn. Acad. Nurs. Sci., 19(3), 28-37, 1999.

2) Reiko Yoshida, Haruo Nagasawa, Kouichiro Kawashima, Yasuto Itoyama:Optimizing university education on intractable neurological diseases through improved information on medical treatment.. Miyagi University Nursing Review, 4(1), 181-185, 2001.

3) Miyuki Nakao, Kumiko Nosaka:Learning and Effectiveness from Simulated Experience for Nursing Students in Japan — analysis of published literature — .Kawasaki Journal of Medical Welfere, 12(2), 97-103, 2007.

4) Midori Yamanishi : Relationship Between Perceived Uncertainty and Adherence in Patient Joining Physical Training Program after Myocardinal Infarction. J. Jpn. Acd. Nurs. Sci., 22(2), 1-10, 2002.

5) Michiko Nogawa : Study on the Reliability and Validity of the Japanese-language Version of the Mishel Uncertainty in Illness Scale-Community Form. J. Jpn. Acd. Nurs. Sci., 24(3), 39-48, 2004.

6) Merle H.Mishel:The Mesurement of Uncertainty in Illnes. Nursing Reserch, 30(5), 258-263, 1981.

7) Takami Kinsyo : Amyotrophic Lateral Sclerosis Patient Uncertainty.Journal ofJapanese Society of Nursing Research. 26(1),79-90,2003.

8) Takami Kinsyo, Fumiko Furukawa, Yoko Miyatake, Mitsuko Omori:Development of a Scale for Chronic Uncertainty in Patient with Amyotrophic Lateral Sclerosis - Early Stage of Development-. Nursing journal of Kagawa University. 11(1), 1-8, 2007.

9) Miyuki Nakao and Kumiko Nosaka : The Analysis of the Report of Immobility to Method of Adult Nursing Education. Kawasaki Medical Welfare Journal , 16(1), 167-172, 2006.

10) Kumiko Nosaka and Miyuki Nakao:Simulated Experience to Adult Nursing Education by comparison with the patient experience. Nihon Kango Gakkai Ronbunsyu Seijinkango Ⅱ 37th, 2006.

11) Kumiko Nosaka, Miyuki Nakao: Meaning of Simulated Experience of Body Immobility by Nursing Students International Council of Nurses, 1339, 2007.

12) Kiyoko Futaesaku , Setsuyo Eto, Kazumi Hukuda et al:Kango gakusei no Sikaku Syogaisya wo Rikai Surutame no Kyoiku Houhou no Kento. KANGO-KYOIKU, 45(9), 778-782, 2004 (In Japanese).

13) Fumiko Yasukata:Gakusei to Tomoni Tsukuru Rinchi Jissyu Kyouiku. Kangokyouiku. (10), 814-825, 2000 (In Japanese).

14) http://www.mext.go.jp/b_menu/shingi/chousa/koutou/018/15/toushin/04032601.htm

15) Keiko Takeda, Yoko Kanemitsu, Yoshiko Hutoyu:Understanding the Problems of the Elderly through a Simulation Experience-Difference in the Effort between Before and After Clinical practice-. Kawasaki Medical Welfare Journal, 11(1), 65-73, 2001.