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SOCIO-PSYCHOLOGICAL PROBLEMS OF PATIENTS WITH LATE ADOLESCENT ONSET TYPE 1 DIABETES — ANALYSIS BY QUALITATIVE RESEARCH —

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ABSTRACT

Purpose: To identify the serious emotional impacts as socio-psychological problems encountered by patients with late adolescent onset type 1 diabetes since their disease onset. *Subjects and methods:* Thirteen patients (aged 21–35 years) with type 1 diabetes, onset age from 17 to 28, were interviewed. To extract their disturbing experiences from the content of the interviews, a qualitative analysis was carried out. We categorized their experiences as socio-psychological problems. *Results:* Twenty-two items of socio-psychological problems which posed obstacles to the control of diabetes were found. Problems with particularly strong impacts included a fulminant crisis prior to hospitalization; surprise and shock of patients themselves and family members upon diagnosis; unacceptable feelings against insulin injections and diabetes; difficulty and anxiety over frequent and unexpected occurrences of hypoglycemia; noncompliance with diet therapy; stress of disclosing the disease to fiancés and their parents; no understanding of or knowledge about diabetes on the part of people around them; restricted range in occupation selection, travel and daily life; existence of stigma; no place for performing insulin injections; resistant or negative feelings against disclosing to others that they had diabetes; acceptance of the disease using various emotional coping behaviors. *Conclusions:* These results suggest that for patients with such problems we should seek a more effective sort of intervention to improve their quality of life (QOL).

Key Words: Type 1 diabetes, Late adolescent, Socio-psychological problems, Qualitative research

INTRODUCTION

Young people with type 1 diabetes experience a great distress in trying to accomplish their “developmental tasks” and meet the expectations of all around them with the daily treatment requirements, including insulin injections, dietary management, therapeutic exercise and self-monitoring of their blood glucose levels. Since the physical and emotional characteristics of patients with late adolescent onset type 1 diabetes are different from those of patients with childhood diabetes, different kinds of care are required compared to patients with childhood or adult diabetes[1]. Late adolescent onset diabetes, however, has rarely been studied due to both

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the diversity of the disease itself and to the problem of a transition from pediatricians who treat the disease in children to internists who treat adults[2,3].

The definition of late adolescence varies considerably from researcher to researcher. In the present study, the period between 17 and 28 when young people graduate from high school, leave their parents' protection and become independent is defined as late adolescence. The purpose of this study is to identify the serious emotional impacts as socio-psychological problems experienced by late adolescent onset type 1 diabetes patients since their disease onset.

Clarification of these emotional impacts would enhance our ability to assist patients who are making efforts toward the treatment and selfcare of diabetes under the double burden of the disease itself and their "developmental task".

SUBJECTS AND METHODS

The subjects were 13 patients, aged 21 to 35 years, who were diagnosed as type 1 diabetes clinically by their doctors between the ages of 17 to 28. They are currently undergoing insulin treatment as outpatients in large or middle-sized hospitals in Aichi Prefecture (4 facilities) (Table 1).

Interviews and analyses were based on a qualitative research design. The design is not a research method aiming to verify such hypotheses quantitatively with clearly defined variables as in the case of the quantitative research ordinarily conducted in the field of health care; rather, it

Table 1. Demographic and clinical characteristics of late adolescent onset type 1 diabetes patients.

Number of cases	13
Male / Female	3 / 10
Age (yrs)	30 ± 5 (21~35)
Onset age (yrs)	20 ± 3 (17~28)
Duration of diabetes (yrs)	8 ± 5 (1~16)
Insulin injection	
two times per day	4
three times per day	4
four times per day	4
CSII	1
Glycosylated hemoglobin A_{1c} (%)	8.2 ± 1.9 (5.9~11.5)
Complications	
none	9
diabetic neuropathy	1
diabetic retinopathy	1
cataract	2
Marital status	
single	5
married	8
Occupation	
housewife	4
student	1
part-timer	1
full-timer	7

Data are n or means±SD (range). CSII: continuous subcutaneous insulin infusion

Table 2. Analytical procedures.

A process of analysis to extract the contents of shocking emotional experiences and to categorize them as socio-psychological problems.

1. Read verbatim records repeatedly. Abstract a series of contexts in the verbatim records which are deemed to express such an experience and code it.
2. Describe the contents and meanings expressed by the context together with the code (It may be a tentative description at a first step and will be revised while reading the context repeatedly, collating and comparing it with comments of other patients who were interviewed and from repeated discussions with coworkers).

<An example of analysis procedures>

Raw data (Verbatim records)	Code	Shocking emotional experiences
Q: How long have you been suffering from diabetes? R: It’s already been 17 years. Q: How had you been until you could have feelings such as those you have now? R: It took a long time. I did not know what kind of disease it was and I was very ashamed of it and I hated others knowing I had it (laughs). I never call it diabetes even at home but call it “such a disease that I have” —Mmm. People are apt to make a fun of diabetes. For example on TV, the disease is often used for laughs, such as “If you eat sweets so much, you will have diabetes!” I wonder why people have such a poor image of the disease (Case A).	Feelings about the disease	I did not know what kind of disease diabetes was (It requires me to continue injections all my life). I was very ashamed of it and hated to have it known by others. I don’t call it diabetes even at home. Diabetes is a disease that is often used as material for laughs on TV (Case A).

3. Divide the contexts describing shocking emotional experiences into groups with similar meanings and contents (Classification).
4. Examine the classified groups of contexts closely and consider the meanings of the shocking emotional experiences included in each group. Abstract the essence of each problem and name it.

<An example of analysis procedures>

Grouping of contents with similar meanings (Classification)	Meanings of shocking emotional experiences	Naming of problem	Naming of episodes	Naming of patients
Feelings on the disease: I did not know what kind of disease diabetes was (It requires me to continue injections all my life). I was very ashamed of it and hated to have it known by others. I don’t call it diabetes even at home. Diabetes is a disease that is often used as material for laughs on TV (Case A). Feelings about the disease: I feel like I’m handicapped. I hate such a feeling and I don’t tell anyone about the disease. That is my secret (Case B). (The rest is omitted)	Diabetes is a shameful disease. I don’t want to tell anybody I have it.	Stress of disclosing disease to others.	16	8

aims to explore the feelings or empirical phenomena of subjects to identify and generalize potentially important variables and concepts[4,5].

Interviews were performed by two interviewers using half-structural questionnaire consisting of the following items: situations of initial onset and first hospitalization, subsequent daily treatment and follow-up clinic visits, efforts at diet therapy, occupational situation, obstacles in daily life, surrounding persons including family, friends and medical practitioners, marriage, childbirth and childcare, and feelings about diabetes. The answers were recorded on audiotape with approval of the patients. After the interviews, all recorded conversations were transcribed verbatim.

To maintain consistency, one of the two interviewers was the same throughout. Each interview was performed following the consent of the subject in a room isolated from others at the hospital where the subject was being treated. The interviews ran from January through September of 1997.

Examples of the analyzing procedure are given in Table 2. During the interviews subjects expressed their feelings and experiences about the events that occurred since becoming diabetic, and the impact these events had on their lives. We extracted and categorized their shocking emotional experiences as socio-psychological problems.

To maintain the accuracy and credibility of our results, all analyses were done by more than two researchers (one of whom participated in all the analyses). When there was a disagreement between two researchers, a discussion by all research members was held to ensure credibility in our interpretations. Moreover, the accuracy of all procedures throughout the study was evaluated by all research members referring to the description by Nicholas and Pope[6].

RESULTS

The verbatim records indicated 331 shocking emotional experiences which were extracted along with the subjects' feelings. They were carefully assessed and classified into five groups by their meaning. The contents of each group were then further reviewed to categorize and identify any socio-psychological problems. Twenty-two such problems were identified (Table 3).

1) Problems concerning onset and diagnosis

Four problems were identified under this heading. The first involved 8 of the 13 patients. They spent a period under physically critical conditions of falling into a coma or pre-coma prior to hospitalization without knowing what was happening in their bodies. The second was a feeling of "surprise and shock on getting the unexpected diagnosis of diabetes". Common reactions included, "Since I am still young and not obese, why do I have to suffer from diabetes?", and "I have no future in spite of my youth" (7 cases). In 10 patients, their recognition of deep grief expressed by their parents, especially by their mother, ("My child has a terrible disease!") were identified and categorized as a problem of "surprise, sorrow and self-accusation among their parents". In addition, 3 patients reported feelings of embarrassment that their condition was not properly diagnosed at the hospital earlier. "I am afraid of having been given improper instructions at the hospital (that is, a hospital without medical specialists for diabetes) I visited the first time".

2) Problems concerning treatment

Three problems were concerned with insulin injections. The first involved feelings of fear and refusal toward performing self-injections at the start of insulin treatment (11 cases). The second was unacceptable feelings against the injections (8 cases); "Injections are too troublesome", "I hate to be seen by others while I'm injecting myself", and "I once contemplated suicide when told that I had to perform self-injections". Moreover, 7 patients stated that "Hy-

Table 3. Socio-psychological problems of 13 late adolescent onset type 1 diabetes patients.

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Problems concerning onset and diagnosis	
1. Physically critical condition prior to hospitalization	8
2. Surprise and shock at unexpected diagnosis of diabetes	7
3. Surprise, sorrow and self-accusation felt by parents	10
4. Feeling of embarrassment in the hospital where patients visited for the first time	3
Problems concerning treatment	
<Insulin injections>	
1. Negative feeling at start of insulin injections	11
2. Unacceptable feeling upon continuation of insulin injection	8
3. Difficulty and anxiety about frequent and unexpected hypoglycemic symptoms	7
<Diet therapy>	
1. Noncompliance with diet therapy	9
2. Feeling of difficulty on starting of diet therapy	5
<Other>	
1. Uncertainty about future	
• Anxiety about complications	6
• Declining physical strength or resistance	6
• Anxiety about bearing a deformed baby	3
2. Abnormality in physical condition caused by treatment	3
Problems concerning marriage, pregnancy and childbirth	
1. Disclosing the disease to fiancé and fiancé's parents	8
2. Feeling handicapped or "different" due to cancelation of engagement or divorce	4
3. Severe vomiting during pregnancy	3
4. Sorrow for experiences of abortion or contraceptive surgery and guilty conscience about being childless	2
Problems in social and daily life	
1. No understanding of or knowledge about diabetes in people around them	10
2. Restriction in selection of occupation, travel and daily life	9
3. Existence of stigma	7
4. No place to perform insulin injection	6
5. Financial burden of treatment	1
Problems of mental attitude toward to diabetes	
1. Positive feelings	
• To have hope	10
• To find out affirmative meanings	7
• Getting used to the disease	5
• Changing one's mind	4
2. Negative feelings	
• Diabetes is a foreign body	9
• Stress of disclosing disease to others	8
• A heavy mental burden because of taking care of it all the time	5
• Servile feeling to others	2

poglycemia can not be controlled", expressing feelings of "difficulty and anxiety over frequent and unexpected hypoglycemic symptoms".

Two problems arose in regard to diet therapy. Nine patients admitted "noncompliance with diet therapy", stating that "I can not always conform to such therapy", and "If my blood glucose level is elevated because of noncompliance, so be it". Six patients expressed "Feeling difficulty upon the start of diet therapy", stating that "Initially, my parents were very nervous about it".

The other problems identified were "uncertainty about future", including anxiety about possible future complications (6 cases), a decline in physical strength and resistance to disease (6 cases), and concerns about giving birth to a deformed child (3 cases).

3) Problems concerning marriage, pregnancy and childbirth

Four problems were identified. The problem which most patients had was a fear of "disclosing to their fiancés and their parents that they suffer from diabetes" (8 cases), including hesitation upon disclosing their disease to their fiancés and some psychological obstacles due to objections from their fiancé's family. Those patients who had experienced a cancelation of their engagement or a divorce because of the disease felt burdened by a handicap that makes them different from others (4 cases).

With respect to pregnancy and childbirth, there were 2 problems, i.e., "severe vomiting during pregnancy" (3 cases), "sorrow over an abortion or contraceptive surgery, and a guilty conscience about being childless" (2 cases).

4) Problems in social and daily life

The following 5 problems were found. Ten subjects reported "no understanding or knowledge about diabetes among people around me". Nine experienced "restrictions in job opportunities, travel and daily life", including such comments as "I got a job in the family business because I felt it was safe". Other problems included "the existence of a stigma" (7 cases), "no place to perform insulin injections" (6 cases) and "the financial burden of treatment" (1 case).

5) Problems of mental attitude toward diabetes

These problems were shown as 2 expressions of feeling. One was to accept the disease positively by having some alternative feelings including having hopes, searching for some positive meanings, getting used to the disease and changing their mind. Another one was the feeling to accept the disease negatively, i.e., diabetes is an unacceptable foreign body; I hate to disclose my disease to others; it is a mental burden to take care of the disease all the time.

DISCUSSION

One significant problem upon the onset of diabetes is that many patients had to suffer a period of time prior to their diagnosis in a physically critical condition of falling into a coma or pre-coma. They were then shocked by being diagnosed with diabetes, and wondered why they had to suffer from such a disease despite the fact that they were still young and not obese. These findings make it clear that a lack of knowledge about type 1 diabetes by the patients as well as their families delayed their first visit to the hospital, thus increasing their risk.

A diagnosis of diabetes had a strong impact not only on the patients themselves but also on their parents, especially their mothers. Hägglöf *et al.*[7] interviewed the parents of children 15 years and under with type 1 diabetes, and reported that the parental state of mind upon the onset of the disease was characterized by strong feelings of confusion accompanied by fear and sorrow, and that the mothers in particular tended to suffer feelings of anger for a long time. Although the age of subjects in their study differed from that in the present study, the reactions expressed by their parents are similar. Consequently, upon a diagnosis of diabetes, psychological support is very important not only for the patients themselves but also for their parents.

Although the patients admitted that insulin injections were essential for survival, they could not completely bring themselves to accept such a lifestyle. Moreover, the start of insulin injections following the diagnosis of diabetes had such a tremendous impact on some patients that they attempted suicide. The incidence of suicide among young patients with diabetes is high in Japan as well as in Europe and the USA[8,9)]. As has been pointed out already, it is important to start insulin injections with the full psychological consideration.

It was reported that patients with diabetes were most fearful of acute complications (coma, adverse effects of insulin and other uncontrollable phenomena) together with chronic ones[10,11)]. In an investigation of university students between 18 and 35 with type 1 diabetes, none of them considered hypoglycemia preventable or avoidable[12)]. In the present study, patients also considered hypoglycemia unpredictable and felt it difficult to cope with. According to the above report[12)], the patients understand that they have to undergo diet therapy but they can not always manage to do so in reality. Although they also think that their friends could help them in an emergency if they knew about their disease, they are so worried about how their friends would react that they do not feel like disclosing it. The present study also provided very similar results. There were many patients who showed noncompliance with the diet therapy, and most of them hesitated to disclose their disease to others.

The Diabetes Control and Complications Trial (DCCT)[13,14)] showed that much more intensive treatment than ever before has been recommended for type 1 diabetes. For type 2 diabetic patients, the UK Prospective Diabetes Study (UKPDS)[15)] and Kumamoto Study[16)] reported the beneficial effect of strict blood glucose control by intensive therapy. Nevertheless, undergoing intensive treatment is a burden on the patients and their families. Despite submitting to such a burden, the blood glucose levels in young patients tend to remain at higher levels than those in adults patients[14)]. Some reports showed that relatively high blood glucose levels in adolescence might be induced by a puberty-specific endocrine mechanism[17,18)]. These findings indicate the difficulty of controlling blood glucose levels in patients with adolescent onset type 1 diabetes in spite of its importance.

The distress felt when patients disclosed their disease to their fiancés as well as the fiancés' parents, their experience of a divorce or cancelation of an engagement because of the disease, and the stigma they suffered in their youth seemed to have left them with a mental trauma that generated a feeling that "I don't want to let others know that I have diabetes because it's a shameful disease". The experiences of severe vomiting during pregnancy, or undergoing an abortion or contraceptive procedure impacted them well beyond our expectations. These results suggest strongly the necessity for special intervention and counseling for adolescent patients on the part of medical practitioners.

It was observed that the patients felt their options limited in their daily activities. In Japan, the rate of people refused employment because of having diabetes is a high 35.3%[19)], while in Australia it is also significantly high in such patients[20)]. The results of the present study indicate that the patients with diabetes tended to get jobs in companies managed by their relatives or family members as sort of protection against being rejected for employment or encountering problems after they are hired.

The present study suggests that patients with diabetes feel that they can not entirely accept the disease and that they spend their lives mentally compromising with it. Delamater *et al.*[21)] reported that a poorly-controlled group used wishful thinking and avoidance-coping behavior more frequently compared to a well-controlled group. Our previous report[22)] on the coping behavior of diabetic patients aged 24 to 74 years showed that patients with a high glycosylated hemoglobinA_{1c} level had significant relation with coping behaviors such as “not accepting the disease as it is” or “not recognizing the disease calmly”. Patients in that investigation were also coping not only by problem solving-patterns but also by patterns of wishful thinking, resignation, and avoidance. These results suggest that although wishful thinking or avoidance behavior is the response of poorly-controlled patients, it may also be a response distinctive to such patients with chronic diseases, which can not be excluded from their daily lives.

In conclusion, there were a number of socio-psychological problems producing obstacles for patients with adolescent onset type 1 diabetes. For effective nursing intervention, we need to be attentive to their deep emotional distress. In further investigations, we should seek more effective interventions to overcome these obstacles, and so improve their quality of life (QOL).

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