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THOUGHTS AND SUPPORT OF FAMILY MEMBERS CARING FOR ADOLESCENT SCHIZOPHRENICS: A TWO-CASE STUDY

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Case Study

Thoughts and Support of Family Members Caring for Adolescent Schizophrenics: A Two-Case Study

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Abstract

Recently, the healthcare strategy in Japan has shifted its focus to regional medical treatment/welfare. However, support for family caregivers is inadequate, and they have to address the many issues that arise from living with an ill family member. Furthermore, with regard to schizophrenics at adolescence (SAs) in particular, issues related to the psychological and emotional development and the career choices of these family members arise coincidentally with the formation of their self-identity, and support demands on family members are substantial. As such, we investigated the thoughts of family members (specifically mothers) caring for SAs, and attempted to determine the kinds of support they require. Semi-structured interviews with mothers living with SAs were conducted, and a qualitative-inductive analysis of the coded interviews was then performed. Data were analyzed with respect to time: viz., data were analyzed so as to determine support needed at the onset of the disease, at the time of the study, and in the future. The participants reported two kinds of regret, which formed negative factors associated with their thoughts of the patients: (i) failure to notice the onset of the disease, and (ii) anxiety about the disease or its progress. Additionally, mothers felt relief when primary medical caregivers listened to them as they related their experiences emotions about their plight and the patient. Their wish to live with patient and their understanding of and respect for the patient remained intact at the time of study. However, impatience was felt by mothers when events were not progressing favorably or as anticipated. Although it varied according to changes in the content, substantial anxiety was prevalent. Worries about the future, such as anxieties and hopes related to the social independence of patient were common, with thoughts tending to be positive when progress was being made. Typical feelings reported by mothers living with SAs included the following: (i) difficulty noticing onset of the disease; (ii) over-protection of patient; and (iii) coexistence of hope and resignation about the patient's future. Furthermore, the mental state of mothers and symptoms of patient were interdependent as caregivers attempted to establish their relationship with the patient. As family members endure the heavy mental and other responsibilities of care, concrete support for the medical treatment of the patient and the daily living requirements of family members are required.

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1 Introduction

After the revised Basic Plan for the Handicapped was announced in 2002, strategies for the focus of hospital treatment shifted to regional healthcare and welfare/wellbeing. However, the support system for psychiatric patients and their family members is inadequate as of yet; the latter especially have to lead a life fraught with many difficulties. In fact, mentally ill family members and the rest of the family exert an enormous influence on each other.[1] Therefore, a support system that focuses on two areas is needed: (i) support for family members providing care for the patient; and (ii) support to relieve the enormous difficulties encountered by the affected family per se.

Schizophrenia patients, in particular, are highly and chronically susceptible to the exacerbation of their condition, likely to be subject to intense discrimination, and isolated and poorly cared for due to the limited availability of social support and understanding. As a result, the physical and mental load on family members caring for these patient is substantial. Additionally, the mere fact that their child happens to have acquired the disease is devastating to parents, and many internal emotional conflicts and obstacles can arise before parents can finally find themselves able to accept this reality. The general course of psychological progress of family members caring for psychiatric patients has been documented;[2] however, coping with a child suffering from psychiatric disease after having overcome the initial psychological hurdles remains an urgent issue.

Given this situation, recent investigations have increasingly focused on not only the patient but also on the care and needs of the affected family[3] as well as on countermeasures for the difficulties facing the family.[4] As a result, previously documented relevant factors,[5] factors providing hope for the family,[6] and the psychological and behavioral aspects of affected families[7] have been well appreciated in recent years. However, in the last decade there have been few or no reports on family members living with schizophrenics at adolescence (SAs).[8] As adolescence[8] is a stage in life where self-identity coupled with the issues of psychological and emotional development and job placement are of concern to the patient, the physical and mental load on the family is projected to be substantial.

During adolescence,[8] family members feel anxiety about the future of their withdrawn young child (hikikomori), and the child him/herself feels anxiety and worry about his/her future,[9] the typical concerns of family members living with SAs remain unknown. Consequently, our present study endeavored to: (I) understand the actual thoughts of family members (mothers) living with SAs; and (II) formulate an appropriate support system for family members living with SAs based on our present findings, especially wherein the support system would prevent recurrence of the disease in patients, as a previous study[10] has provided evidence that such recurrence can be prevented through the development of useful family relationships .

2 Methods

2.1 Study design

Qualitative study: Investigating the actual thoughts, problems, and methods of addressing the typical concerns of family members living with SAs, and formulating a support system for these families.

2.1.a Subjects

The participants were family members (specifically mothers) living with SAs whose current daily life activities (DLA) were under control and whose family members were thus in a position to reflect on past events. Family members of patients who still experienced convulsions during their DLA at the time of study were excluded from participation.

2.2 Investigational Methods

2.2.a Semi-structured interview with interview guidelines

With the consent of their respective families (mothers), semi-structured interviews of two SAs being treated in a Psychiatric Healthcare Center in Prefecture A, were conducted for 30-60 min periods. The interview guidelines were publicly accessible to participants when and where appropriate. Recording of interviews was performed only when consent was obtained.

2.2.a.1 Questions related to basic information and replies from family members included the following:

i) For patients (status during the study or current): age, gender, duration since onset of disease, hospitalization history (absence/presence of hospitalization, total length of hospitalization), whether receiving care at home with family or in hospital and absence/presence of support system, use of social resources (workplace, daycare, life-support center, visits, nursing care, etc.), frequency as an out-patient, and major lifestyle factors (work, school, housework-helping, stay-home, etc.); and ii) family members (status during the study): age, gender, relationship with patient, major lifestyle factors (working, housework, care for patient, etc.)

ii) Interview with participants included the following questions (current: during the period of study):

1 How is your time currently spent?

2 What are your thoughts about your current life (i.e. thoughts about the affected family member, and thoughts and feelings or lack thereof with regards to living with the affected family member)?

3 What difficulties have you encountered living with an SA-affected family member?

4 What or how did you feel about the state, character/personality, and lifestyle of your affected family member after onset of the family member's disease?

5 What was/were the factors that made you decide that the affected family member needed to be diagnosed (e.g. realizing the need upon observing the family member, an event occurring as anticipated via concrete events through experiences)?

6 How did you perceive and feel about the future of your family member now or after the onset of their disease (including: intention to make use of societal resources or to resort to individual effort; anxieties, expectations, or hopes with regards to their family member's future)?

7 In cases where the affected family member has siblings, how did the siblings interact with the family member (e.g. how did the parents expect the sibling to support the affected family member)?

8 How have events progressed and changed since the onset of the disease (e.g. events that have changed due to a particular episode of the disease, and what event triggered the episode, e.g. a naturally occurring event, or a pre-meditated or conscious act aimed at causing change)?

Participants were encouraged to speak freely and at ease about the above questions, without restrictions being placed on their answers.

2.2.b Ethical guidelines

Participants gave written consent after being briefed on the following:

1. the research purpose and the motivations, methods, and significance of the study:
2. how to meet their needs and convenience with regard to the itinerary, place, etc.;
3. they would be identified only as A, B, and so on so as to avoid revealing their actual identity;
4. participation was based on free will;
5. refusal to participate would not result in lower qualitative and quantitative services, or any

other disadvantages;

6. they were not required to discuss any matters they did not wish to;
7. each interview was scheduled to last 30-60 min in principle. Their personal circumstances would be accommodated and their wishes would be respected according to their needs;
8. they would be encouraged to speak at their own pace and at ease;
9. recorded interviews would be filed and locked with passwords during storage; the use of the recordings outside the research study would be prohibited;
10. the recordings would be erased when the research study was completed;
11. they would free to terminate their participation at anytime during the study;
12. whenever and wherever possible, interviews would be conducted in private rooms to protect privacy;
13. the study would been conducted according to and be subject to approval of the ethics committee of the investigational cooperation facilities.

2.2.c Analytical methods

Recorded interviews were transcribed word-by-word, and the recordings were played repeatedly in order to ultimately be able to accurately arrive at their intended meaning using qualitative induction analysis. Based on this analysis, they were rewritten in the form of full sentences expressing their intent using words used by the participants when and where appropriate; thereafter they were coded. Sentences expressing similar intentions were next categorized, and given names of higher abstract levels to place them under subcategorizes. The the relevance of the derived subcategories was analyzed, simlar subcategories were combined and made into new categories. . Thereafter, the sentences were grouped according to whether they referred to past, present, or future events or feelings, and categorized accordingly.

3 Results

3.1 Profile of the SA patients living with the participants of the study

Interviews were conducted with 2 participants (herein referred to as A and B; both were from District D), who were mothers of SAs. Both A and B suffered from parkinsonism; A was in her early 70s, while B was in her late 60s

Case A: At the time the study was being conducted, A’s son was in his late 30s, had been suffering from SA for a 13 years, had been hospitalized three times, and was living with his mother (A) with no support from any other sources. He commuted to the mentally handicapped (MH) workplace 5 days a week (from 09:00 – 15:00 hr on normal working days), and visited the clinic as an outpatient once every 2 weeks. Although he had been working previously, he had to go to the MH workplace after the onset of SA.

Case B: As to participant B, at the time the study was being conducted, her daughter was in her late 20s and she had been suffering from adolescent schizophrenia for 6 years. She had been hospitalized once, and she was living with her parents (i.e. a family of three). Her mother, the participant, had a sister living nearby and although the she was willing to provide support, the support could not be realized due to conditional inconvenience. Due to his tight work schedule, the patent’s father could not help either. The patient helped out with household chores, and visited the MH workplace once or twice a month, and the clinic once a month as an outpatient. Although she had been employed previously, after the onset of AS, she remained at home during the day (Table 1).

Table 1. Overview of study: situations of participant and patient at the time the study

Patients	**Ms. A**	**Ms. B**
Age:	Early 30s	Late 20s
Sex:	Male	Female
Diagnosis (duration):	Schizophrenia (13 years)	Schizophrenia (6 years)
Prior Hospitalizations:	3 hospitalizations	3 hospitalizations
Family Support:	Key Support: Mother; mother and child lived together without other supports.	Key **Support: Mother** **In addition to the patient's parents, patient's sister** lives nearby, and is willing to provide support. However, father of patient cannot provide support due to work schedule
Use of Social Resources:	Mentally handicapped (MH) workplace: 5 days a week (weekdays 09:00 to 15:00 hr)	MH workplace: One or two times a month
Frequency of Outpatient Visits:	Once every two weeks	Once a month
Lifestyle:	Although the patient had been working, he went to the MH workplace after the onset of SA and often stayed home. The patient did not speak with mother.	Although the patient had been working, she helped out with household chores after SA onset.
Participant	**Ms. A's mother**	**Ms. B's mother**
Age:	Early 70s	Early 60s
Sex:	Female	Female
Relationship with the Patient:	Mother	Mother
Lifestyle:	Housework and care of patient	Housework and care of patient

3.2 Thoughts of family members (mothers) living with AS patients (Table 2)

3.2.a Previous status (about the time of AS onset of her child)

3.2.a.1 Previous anxieties (P/anxieties)

P/anxieties, were divided into 3 categories: anxiety related to child's life in general (P/anxiety-LG); anxiety related to child's treatment (P/anxiety-T); and anxiety related to the progress in the child's condition/symptoms (P/anxiety-C/S). P/anxieties were greater with regard to the disease-related categories, i.e. greater for P/anxiety-T and P/anxiety-C/S, than with daily life activities (DLAs) or P/anxiety-LG. With regard to P/anxiety-LG, the children tended to stay mostly in bed at home, raising the mother's concerns about their own and the child's future. Additionally, although the mothers desired their child to have a job, there was also anxiety as to how well their child would be able to cope with working. As for P/anxiety-T and P/anxiety-C/S, cumulative anxieties about the current treatment, appropriateness of the treatment, and the progress of disease/symptoms continued to plague the mother. Furthermore, although anxiety over their in-hospital DLAs while the child was hospitalized weighed upon the mother, the mother was aware that hospitalization was to the child's benefit.

Table 2. Family thoughts that living with schizophrenia patients at adolescence

Period	Category	Subcategory	Code
Prior / At Disease Onset	Anxiety	Anxiety about life in general of the patient	I wonder if my child is fine just sleeping.
			What will become of them in the future?
			I wonder if my child can work.
		Anxiety about the treatment of the patient	I wonder if the medicine has worked.
			Only the amount of medication increases; medical caregivers are not listening to my thoughts and feelings..
			I wonder if it is such a good thing for my child to be hospitalized
		Anxiety about the medical condition of the patient	Do not know about the disease and symptoms
			I feel anxiety about my child feeling isolated
	Regret	Regrets of interacting with child	Isolated child without knowing
			Thought the child was normal
			Did not come in contact with child.
		Regret not noticing the disease onset	Did not care about the child
			Failed to notice the disease.
			Doubted it was a case of the disease.
			I thought my child's symptoms were just the signs of puberty
	Relief	Relief due to the verbalization of their own thoughts to medical staff	Medical staff listened to my thoughts.
Current/ At Time of Study	Anxiety	Anxiety about life in general of the patient	I wonder if my child is fine because he/she is just sleeping all day.
			My child has no goals in life.
			I am worried my child feels isolated.
		Anxiety about the treatment of the patient	I wonder if the amount of medication is appropriate.
		Anxiety about the medical condition of the patient	I feel anxiety that the condition is getting worse.
		Anxiety about their own health	It must also keep healthy (for my child's sake)
			No particular reasons; just being concerned
	Impatience	Impatience about self-reliance of the patient	I want my child to take steps in the direction of self-reliance.
		Impatience that I must change the patient	I want the patient to become stronger, even a little.
			I want the patient to improve their personal appearance.
			I want the child to change, even with the help of others.
	Respect	Eagerness to respect the patient's wishes	I most want to respect the opinions of my child.
			Not pinching the cheek or mouth of child.
	Hope	Hope the patient will actively engage in activities outside home.	I want my child to affirmatively go to work.
			I also want my child to engage in other outside activities.

Table 2. Family thoughts that living with schizophrenia patients at adolescence

Period	**Category**	**Subcategory**	**Code**
	Hope	Hope the patient will be healthy	I want my child to have a healthy life.
			I want the patient to be strong.
		Encouragement carry on with life for the sake of the patient	I do not wish to die while leaving my child on their own.
			The time I spend with my child is precious.
	Relief	Relief derived from the patient or their status.	Recently my child has become more active.
			The disease has been in remission recently.
			I can speak with my child at any time.
			Other family (e.g. sister) can help me care for my child.
			My child's medical condition is stable.
		Relief derived from the presence of others who they can relate to	I can exchange sympathy with others in a similar situation.
			People with the same disease are enjoying life.
		Ability to calm feelings	I can try not to hurry and to take life slowly.
			I am able to maintain the status quo for the time being.
			I am trying to think positively.
		Relief to the medical caregivers	I feel relieved by the presence of others who are trying to understand and take care of my child.
	Understanding	Understanding of the patient's disease	I need to understand my child's condition.
Future	Anxiety	Anxiety about the social self-reliance of the patient	I want my child to find work without having the disease known
			I wonder if my child will be able to be self-reliant.
			My child's future is uncertain.
		Anxiety about life in general of the patient	After I die, what will happen to my child?
			Will my child be able to find a marriage partner who can understand her condition?
		Anxiety about the medical condition of the patient	My child's condition might worsen again.
	Resignation	Resignation about the social self-reliance of the patient	It is difficult for my child to find work.
			I have hopes, but these could be merely dreams.
			My wishes may not come true.
	Hope	Hope that the patient will be self-reliant	I want the patient to be self-reliant.
			I want the patient to find work.
			I want the patient to enjoy life.
			I hope my child has a bright future.
		Hope of the region with respect to facilities and systems	Good to increase the facility to support the mentally handicapped in regions
			It is a good thing to create the opportunity to discuss, such as worries about the disease in regions

3.2.a.2 Previous regrets (P/regrets)

P/regrets, were divided into 2 subcategories: regret about not staying in closer contact with the child (P/regret-A/C), and regret about not noticing the disease (P/regret-NK). With regard to P/regret-A/C, the mother thought the child was self-reliant, and was acting independently, and therefore she felt regret about not staying in closer contact with their child. In P/regret-NK, the mother found it difficult to come into contact with child during puberty and adolescence, and therefore did not provide adequate care for child during this stage of their development. Although laden with P/regret-A/C and P/regret-NK about how she raised the child during this stage, the mother had not expected her own child to develop a psychiatric disease.

3.2.a.3 Previous feeling of ease (P/ease)

P/ease reflected the security derived from speaking about their thoughts to the physician. Not being well informed about the disease was a substantial cause of anxiety; however, mothers derived p/ease from conversations with the physician, even if they were just being listened to by the physician without any response.

3.2.b Current (in-study) status

3.2.b.1 Current anxieties (C/anxieties)

Current anxieties, or C/anxieties, were subdivided into 4 subcategories: anxiety related to life in general of child (C/anxiety-LG), anxiety related to treatment of child (C/anxiety-T), anxiety related to the progress of the disease in the child (C/anxiety-DC), and anxiety related to their own health (C/anxiety-SH). C/anxiety-LG, which emerged gradually, reflected anxiety and dissatisfaction with the child's frequent staying in bed without exhibiting any purpose in their life. Additionally, Current regret-A/C (C/regret-A/C) reflected the fact that the mother reprimanded herself for leaving the child alone unattended. As for C/anxiety-T and C/anxiety-DC, mother expressed concern about drug dosages and the exacerbation of symptoms as a result of knowing more about the treatment/disease than before, as mother was currently reading books about the disease/treatment. With respect to C/anxiety-SH, the mother was anxious for the future of the child, and emphasized her concerns about leaving the child on her own once she passed away, as she was the key person involved in her support. These anxieties and concerns for the child were thought to be likely to persist into the future.

3.2.b.2 Current Impatience (C/impatience)

C/impatience (with certain degree of panic) was divided into 2 subcategories: impatience about the child establishing independence (C/impatience-I), and impatience about the need to change the current status of the disease/patient (C/impatience-S). C/impatience-I is closely linked to the aforementioned anxieties; the mother emphasized that movement in the direction of independence should be taken as the present status of the child was highly undesirable. Mother thought a strong emphasis should be placed on C/impatience-S, and wanted the child to be able to at least manage her own personal affairs and be able to mix freely with others. Additionally, mother wanted to change the current status of the child even if she had to get help from others.

3.2.b.3 Resigned feeling (F/resigned feeling)

As to a sense of resignation about the future, F/resigned feeling, the mother specifically felt a sense of resignation with regard to the future social independence of the child. The mother felt she already had her hands full in the present situation, and that thoughts of hopefulness towards the future (F/hope, described below) were just dreams. Although F/hope existed, F/resigned feeling towards the present condition somewhat prevailed over it.

3.2.b.4 Future hope (F/hope)

F/hope was divided into 2 categories: hopes with regard to the child's independence, work, and relationships (i.e. marriage) (F/hope-I); and hopes with regard to proper regional facilities and the health care system (F/hope-FS). F/hope-I encompassed the mother's high hopes for the child's future with regard to success at work and getting married and providing her with grandchildren. As for F/hope-FS, this encompassed thoughts about the child being able to enjoy a more comfortable life if the regional system could be further developed to provide better support for patients.

4 Discussion

4.1 Time sequence-related thoughts for family and suggestions for nurses

4.1.a P/thoughts (from around the time of disease onset)

Of the three categories related to the time of onset, anxiety was the most likely to be mentioned. Of the 3 subcategories of anxiety, P-anxiety-T and P/anxiety-C/S were more often talked about than P-anxiety-LG: viz., anxiety over the efficacy of prescribed medication, and whether the medications would help the child if hospitalized. Doubts surrounding treatment appeared when the child's condition did not improve despite taking the prescribed medicines and the patient being hospitalized. In addition, our findings concurred with previous findings by Furuya et al.[11] where the family's thoughts at the time of the onset of the disease were ‘inability to psychologically cope with ongoing events due to lack of awareness of the events happening during disease onset.’ This psychological reaction (anxiety) was probably due to inadequate knowledge about the disease in general. Because of this lack of knowledge, family did not understand what was going on, and therefore did not know how to cope with the onset of the disease and what to do for the child, thus inducing anxiety.

Furthermore, when hospitalization became imminent, the family ‘experienced self-pity with regard to feelings of inferiority arising from the social stigma of seeing their own child (i.e. the patient) being hospitalized in a psychiatry department in contrast to their former safe and independent situation.’[11] Our study further revealed that the family felt concern about the child being hospitalized (i.e. leaving the family), anxious about being unable to provide care and not having the child near at hand, and doubtful that they would be happy if the child were hospitalized. The participants in our study were more protective of the child compared to those investigated by Furuya et al.[11] This is probably because participants were family members of adolescent schizophrenics (ASs). In our study, participants especially felt P/regrets about: not being able to raise the child in a normal and proper manner during puberty, having overlooked the disease due to limited interaction with child, and believing they had contributed to the disease onset. As such, the mother tended to feel strongly committed to protecting her child in order not to allow recurrence of this kind of event (i.e. onset of disease): viz. both of the negative categories of thought – P-anxieties and P-regrets – were prominent at the time of onset of the disease.

However, it is to be noted that appropriate care for the patients by physicians provided a sense of relief and security to the family. As such, physicians not only looked into the various anxieties but also monitored if these anxieties were plaguing the family, and inquired as to what the family desired as well as listened to what family members wanted to talk about. Additionally, the physician plainly and concretely explained to the family the following: what was actually happening to the patient, what treatments were being given, and what family members should do to cope with the situation; this provided further relief to the family. Basically, family members are required to understand that ASs need family support to lead a normal life. Therefore, when the patient is admitted – especially the first time - to the hospital, it is useful for nurses to assess the level of knowledge and understanding of family members about the disease and the patient's stay at the hospital. Furthermore, if patients are at the acute stage, physicians should not merely focus on the patient, but should dutifully and consciously approach the family with confidence so as to provide the aforementioned support to the family. In so doing, the family members' P-anxiety and P-regrets can be attenuated and their expectations with regard to the role of the physician can be satisfied. The cause-and-effect relationship that exists between failures at this critical time and eventual P-anxiety and P-regrets, shows the crucial importance of the link between establishing a good relationship between family and care staff and the prevention of the recurrence of symptoms in patients.

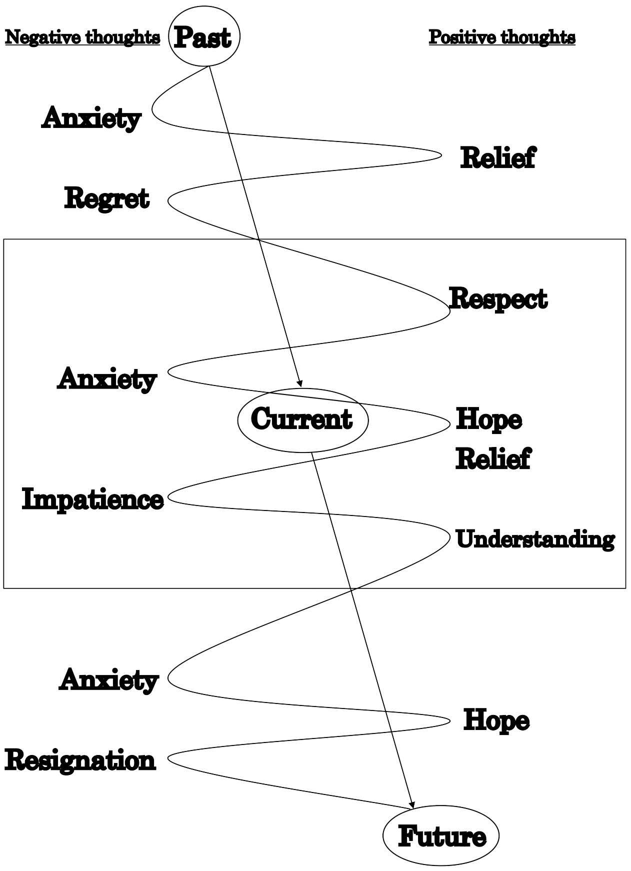

Figure 1. The flow of the family's thoughts

Moreover, lack of knowledge about the disease by family members (mothers) affects the stage before diagnosis of the patient (child): viz., it can lead to families not noticing the disease symptoms even when they are already apparent in the patient. This tendency to be ignorant of disease symptoms is typical in families with children in puberty or adolescence. In the case of adult onset, most patient would have already become independent, and any change in behavior would quickly be noticed by the patient's partner or by surrounding associates and friends of the same age-group in society. Furthermore, in cases where the onset occurs before adolescence, these children are likely to feel less psychological distance from their family, and thus abnormalities would be more easily noticed by their family, as younger children are under greater and more frequent supervision by responsible family members than adolescent or pubescent children. However, as pubescent/adolescent children are facing significant challenges related to physical, emotional, and mental growth as well as career development while at the same time trying to establish independence, there is a tendency for them to be more secretive and private, and to favor associating with their peers more than their family, thus creating a greater gap and less frequent contact between them and the family than is the case with younger children. It is during this developmental stage that family members should take notice of any abnormal changes in their adolescent famil members even if these are not psychologically changes. Apart from being sensitive and easily influenced by surrounding events, pubescent/adolescent youth often will keep their worries to themselves, thus camouflaging disease-induced symptoms from family members. With the currently increase in the number of ASs, especially within the children in their late teens and early 20s, physicians not only have to disseminate relevant information directly to patients and their families, but also expand the flow of information to encompass the society at large, in order to raise awareness about early diagnosis of these diseases in pubescent/adolescent children. We and others[11] have found that, out of a strong desire to work, certain ASs would hide their clinical condition during interviews, and Furuya et al.[11] have further revealed evidence that the society as a whole discriminates against psychiatric patients. In 2004, although the reformed version of public mental health, medical, and welfare agencies have made efforts to disseminated information to the public to the effect that ‘psychiatric diseases are similar to lifestyle-related diseases that all are at risk of suffering from acquiring, and where the cognitive level of ASs is more than 90%,' nonetheless social discrimination against ASs persists as manifest by the difficulty many people in current Japanese society still have accepting these facts. Therefore, while dissemination of the aforementioned information should continue, efforts and activities must be simultaneously undertaken to reduce and eliminate societal discrimination.

4.1.b Current thoughts (C/thoughts)

C/anxieties appeared to be different from P/anxieties, in that these worries were reduced through cumulative pooling of knowledge and experience of treatments and symptoms. However, C/anxiety-LG was greater than P/anxiety-LG. With respect to independence with respect to DLAs, while previously the participants had not been hopeful (P/hope), by this point they had begun to express hopeful thoughts about their situation (i.e. C/hope). In addition there was a reduction in worry over: 1) the current condition of the disease, which had stabilized without acute events; and 2) the ability of the child to get a job in the future (due to unfavorable events that had occurred during prior employment); furthermore, there was an increase in 3) C/hope as knowledge about the disease (Fig. 1) increased. In general, a rise in C/hope is thought to be attributable to the existence of social adaptability that would enable a patient to weather future challenges. However, the mothers in this study were able to entertain great hopes and expectations for the patients because of their poor understanding of disease-induced DLAs. This therefore suggests that it would be difficult for a poorly informed family to concretely understand the impairments to ordinary DLAs on the patient on discharge from the hospital, even if they have acquired some basic knowledge of the disease. Previous findings have suggested that if a family appreciates the impairments to DLAs experienced by the patient/child, and builds a strong relationship with an affected family member, recurrence of the disease can be prevented. In other words, these reports have highlighted the importance of the family-child relationship. As such, nurses are now required to coach affected families on concrete guidelines (especially after discharge) and other information related to challenges faced by patients in performing DLAs.

Apart from the findings above, many others have pooled on C/relief versus P/relief as well. C/relief was similar to P/relief in the sense that it encompassed relief due to physicians being able to listen to their stories and concerns, from others sharing empathy with them, and most relieving of all, from seeing the condition of the patient stabilize. However, findings revealed that the mothers exerted themselves beyond their means to stabilize their feelings, inducing substantial anxiety as a consequence. Additionally, they began to think of understanding their diseased adolescents. Previously, the mothers had been poorly informed about the disease, and they had P/regrets about not noticing or overlooking onset of the disease due to inadequate understanding of their child. A desire to deepen their understanding of their child arose. Furthermore, although they wanted their child to develop as best they could hope for, they could not accept the fact that their child was mentally ill. Compared to prior periods, many positive thoughts naturally emerged in several directions about the future of the child. However, along with these positive feelings of hope, understanding, and respect, negative emotions such as impatience over a lack of or slower than expected set of perceived changes or pace of development emerged. Moreover, whatever goals that could or ought to have been begun sooner, such as before onset of the disease, that still remained yet be accomplished also engendered strong feelings of impatience. Pressure exerted on the patient by family members can increase risk of recurrence;[13] mothers were therefore persuaded to assume a gradual posture void of impatience in order to help their psychiatrically ill child adapt to the norms of society. As a result, one improvement in the support system for such families would be for nurses to be advised to offer family members the follows: counsel on the importance of moving forward with patience; detailed descriptions of, and guidelines on, DLAs and the nature of SA symptoms without conferring excessive expectations or hopes.

Thus, in this manner, with regard to C-anxieties, participants were able to acquire positive thoughts that they had never had before, and a positive outlook was gradually evolving despite substantial anxieties lingering on. As a result, mothers continually took actions (e.g. encouraging the patient to build up physical strength and venture out from home to mix with others in the outside world) to support their child in developing independence, as if to neutralize their anxieties. Furthermore, as mentioned above, mothers harbored C/impatience mingled with hope about their child's independence, and the more hope they espoused, the more they tended to keep close to their children, thus merging the feelings of the family and child.

The pattern of psychological development in the patients observed in this study resembles that from previous findings[14]. Improvement in the health condition of the patient markedly improves the psychological status of family members, which may be attributable to relief due to concerns about the patients per se (relief-C) (Table 2).

4.1.c Future thoughts (F/thoughts)

As with the other times periods, thoughts about the future elicited anxiety (F/anxieties), although the contents were different from previous time periods. P/anxieties were mainly focused upon P/anxiety-C/S and P/anxiety-T. Additionally, the categorizations of F-anxieties and C/anxieties were similar but held different implications as to the aspect of independence. In C/anxieties, independence meant the patient was able to manage DLA and was venturing outside of family and mixing with others. However, in F/anxieties, independence strongly implied social or material independence per se, such as the ability of the patient to perform work and make a living, or to get married and have a happy family life. As the implications of independence differed in C/hope and F/hope, the increased tendency is said to represent anxiety.

Moreover, a previous study has suggested that the fact of the child being the patient is a load on the family;[11] however, the present findings revealed that C/hope was more related to the child having a purpose in life than to thoughts about the child being a load on the family. In another study,[15] the following 6 factors resembling the category 'hope' in our study contributed to the maintenance and promotion of hopefulness about the patient in the family : information that helps them to expect a favorable future; existence of supportive human relationships; trust of participants in technological improvements in treatment; a feeling of purpose in life for the family member; greater self-confidencein the participants; and 'existence of close attachment between the child and the family member'. However, the present data are more closely related to favorable expectations about the future, and strong expectations of future due to the patient's youth are harbored by family members. This tendency seemed to be the special feature of the affected family members, who hope for the patient to lead a normal life in the relevant community.

As for the typical features of F/thoughts, feelings of earnest hope and, at the same time, resignation, seemed to arise concurrently. Of the various thoughts, the participants appeared to espouse earnest hope without understanding the actual disease state of child, and as data reflecting hope mixed with resignation appeared, participants had to realistically face up to issues encountered/expected. In other words, participants live with complicated thoughts, as hope was mixed with resignation as they became more realistic.

F/thoughts filled with growing assurance and hope, a thought which is highly desirable, served to give the affected family energy for them to carry on living. In addition, the affected mothers faced problems steadfastly and considered how to realistically handle the situation despite feelings of resignation: i.e. overcoming the odds by facing life with a positive attitude. When affected family members overly embraced hope, they lost sight of reality; yet if they over-emphasized resignation, they lost the energy to carry on. Therefore, in an improved support system nurses should be advised to aim to provide a sufficient but not excessive degree of hope to family members so they can face the future without excessive expectations and to help them maintain a balance between hope and resignation to prepare them for dealing with the future. For example, when feelings of resignation prevail, encouraging words such as "Don't give up. Let's try harder," are inappropriate; instead these words should be replaced with "Observe the present state of your child closely …", or "you have now appropriately recognized the situation …", or "Well, what is the biggest problem that is causing your anxiety …" In so doing, family members will avoid disappointment; instead of leading to resignation, the actions and words of affirmation of the nursing staff will be received by family members as words they need to hear. Nurses should continually assess the positive or negative tendencies of the family, and when necessary respond physically or verbally in a manner appropriate to situation.

4.2 Flow of family thoughts from previous to current and future thoughts/events

The thoughts of participants were unstable. When the flow of thoughts is plotted, one can see (in the arrows in Fig 1) that they went from the negative to positive in an meandering fashion.

Participants were living with two negative thoughts - P/anxieties and P/regrets – and few signs of any hope. Even as they were living under a burden, there were moments of relief and positive mood, for example, when physicians were willing to listen to their feelings. The past had been almost entirely filled with negative thoughts with few signs of positive thoughts; however, they were currently living with more positive than negative thoughts. While hitherto had been initially overwhelmed with a variety of experiences and knowledge reltated to their situation, by this point family members became less emotional when seeing and thinking about their child; that is to say, the kinds of thoughts they had towards the the child's DLAs changed. The nature of the anxiety changed, albeit on the whole anxiety as a factor per se remained substantially unchanged. Life was previously primarily filled with negative thoughts; however, certain thoughts (filled with positive elements because of current emergence of positive thoughts about life) neutralized the inclination to enter into a vicious circle of negative thoughts. As a result, their current mood became more positive, with moments encompassing great hope with regard to their child's social independence, although negative thoughts clouded with anxiety and impatience remained.

As for F/thoughts, anxiety about their child's independence remained unchanged, and mothers' hopes were enhanced as the patient's condition stabilized, thus helping the family live a life focusing on positive thoughts about the future. However, one special feature of this situation was the simultaneous existence of contrary/conflicting feelings (e.g. resignation). Although the hope of living a life focusing on positive thoughts, feelings of resignation about the future – such as that nothing comes from hope alone - came and went so that as a whole their lives were filled with a mix of positive and negative thoughts.

The theme of present study is ‘thoughts’ which were perceived according to the particular perspectives of different individuals. Therefore, the results of the study may not be easy to replicate. Moreover, the study was restricted by the following factors: the study was conducted at a single site; there was limited time for data collection; the questions required many details; and the interview process re-exposed family members to unpleasant experiences/events. Furthermore, the number of interviews was limited in time and so as to be convenient for the patient's family: i.e. they were to be held at times when the patient's symptoms were stabilized. Therefore, the results cannot be generalized. Moreover, the results reflect interviews with mothers who wished to live with the child in their own community, or which implied that family members had adjusted their thoughts to those of patient, thus forming a deep attachment. This attachment bias limits the general replicability of these results.

However, the findings of the present study were based on family members living with the SAs. Hitherto, documented literature in the last decade had not focused on SAs. Therefore, the present findings may be of significance. Based on these results, future studies are warranted to increase the number of participants using internal extraction of affected family members' thoughts alongside more detailed analyses of relevant issues.

5 Conclusions

Throughout this study, mothers of SAs exhibited the following concerns: difficulty in noticing the onset of the disease; a tendency to strongly emphasize the importance of protecting the patient due to regrets from not noticing the onset; and high hopes for the patient’s future albeit coupled with strong feelings of resignation. In addition, family members felt relief when they were supported by the existence of peers, when they received understanding and help from physicians, and when patients' symptoms improved. By providing support to patients, family members felt they underwent the same process the patient experienced (from negative to positive thoughts) to develop empathy with them.

Family members living with SAs had a variety of reactions in the course of experiencing the onset of their child's disease and the hospitalization and discharge of their ill family member from the hospital, warranting more affirmative and active support on the part of medical providers. Moreover, as family members harbored tremendous anxieties and impatience, a great emotional load burdened them, and thus this psychological burden could contribute to recurrence of the disease in the patients. Therefore, hospitals and regional social support facilities should provide not only medical care for the patient but also psychiatric care and other support to family members.

One conclusion to be derived from this study is that it is important to put effective practices into place by first observing the ‘shock’ and anxieties experienced by family members of patients during the early phase of hospitalization, where the medical providers can express an attitude of commitment to the family members facing this difficult situation by providing caring and empathetic support and by conducting interviews with them when and where appropriate.

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