Questionnaire about Informing Turner Girls of the Medical Condition

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Introduction

Wakaba’s Society is a group consisting of girls/women with Turner syndrome and their families living in Tokyo and its suburb area. It has been nine years since the society was founded. In July 2005, the number of families totaled 124: 7 subjects aged from 0 to 6 yr, 19 from 7 to 12 yr, 22 from 13 to 18 yr, 60 aged over 19 yr, and 20 supporting members. Many parents are deeply worried about such problems as when, by whom and how their children should be informed of the fact they have Turner syndrome. Since the children feel something is wrong with themselves, some lose confidence in their parents because they don’t tell them anything, and as a result both parents and children become distressed themselves.

Taking this situation into consideration, we carried out an investigation into how the parents and the Turner subjects dealt with the difficulty of informing Turner subjects of the medical condition at the end of 2003.

In Japan people tend to use the Japanese word kokuchi (=disclosure), but we prefer using the word setsumei (=inform) because hearing the word kokuchi make us think of severer diseases such as cancer.

Subjects and Methods

The survey was conducted at a regular meeting of Wakaba’s Society (Dec. 2003), where both parents and affected children were given the questionnaires individually.

The questions were as follows:

1) Questionnaire to parents:
   (1) Please write down answers to the following questions:
      a) When was your child diagnosed as having Turner syndrome?
      b) When did you inform your child of her short stature, hypogonadism and probable infertility?
      c) Who informed or is going to inform your child?
      (2) Do you consider it necessary to inform your child of the medical condition?
      (3) Have you had any trouble about informing your child of the medical condition?
      (4) With whom have you talked about the matter?
      (5) Did you feel you have done good by informing your child of the medical condition; what’s the reason?
      (6) Did you feel sorry about having informed your child of the medical condition; what’s the reason?

2) Questionnaire to Turner girls:
   (1) By whom were you informed of the fact you are suffering from Turner syndrome?
   (2) Who do you think would be the ideal person to inform you of the medical
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(3) When did you learn of your medical condition?
(4) When do you think would have been the best time for you to have been informed?
(5) Have you ever had any anxiety or doubts about your predisposition before you were informed of the medical condition?
(6) Please write down your experience if you have gone through any mental changes since being informed of the medical condition.

Results

The questionnaires were distributed to 46 parents and 22 Turner subjects, of whom 21 and 17 answered, respectively.

The results of the survey given to parents are shown in Fig. 1 (a)~(d) and Table 1.

Figure 1a shows when the child was diagnosed with Turner syndrome, how old the child was when informed, what kind of things they told the child, and who actually informed the child of the medical condition. All the parents who answered the questionnaire said that they consider it necessary to inform their child of the
medical condition. However, they worry about who should do so and how (Fig. 1b). To question 1) (4), 70% replied that they talked with other members of Wakaba’s Society and 17% with their doctor (Fig. 1c). Figure 1d shows the answers to question 1) (5), and Table 1 shows the results to question 1) (6).

The results of the survey given to Turner girls are shown in Fig. 2 (a)–(e) and Table 2. The persons who informed them of the medical condition, question 2) (1), were “my parents” or “a doctor” proportionately 39% for each, and “both my parents and a doctor”, amounted to 11% (Fig. 2a). About the ideal person to inform Turner girls of the medical condition question 2) (2), 80% of the Turner subjects chose their parents as the ideal person, 10% their doctor, and another 10% both their parents and their doctor (Fig. 2b). Regarding the times when the Turner girls learned of their medical condition, question 2) (3), 50% of the Turner subjects replied in elementary school, 7% in junior high school, and 36% in high school or later (Fig. 2c). About the best time to be informed, the question 2) (4), the answers varied from 10 years old to 18 years old (Fig. 2d), reflecting differences in the ages children were diagnosed, family environment and their relationship with their parents. Seventy-six percent of the Turner subjects felt an anxiety or doubts about their predisposition before they were informed of the medical condition (Fig. 2e), and Table 2 shows the answers to the question of whether they had experienced any mental changes.

**Discussion**

**Questionnaire to parents**

It is clear from Fig. 1a that the parents are serious about informing their children step by step...
of such symptoms as short stature, hypogonadism and probable infertility. Although they were very few, four parents had informed their children of all the problems at once: two cases in which the child was diagnosed in infancy and another two cases in which the diagnosis came some time between the child’s fourth grade of elementary school and third grade of junior high school. As for probable infertility, seven parents had not yet decided when they would inform their child of the problem. In general they would like to tell their child about the short stature before the start of growth hormone therapy and to inform of hypogonadism before the estrogen replacement therapy. However about probable infertility, there is no consensus among the parents as to when to inform their child or

Table 1  Questionnaire to parents: Did you feel sorry about having informed your child of the medical condition, what’s the reason?

- It is regrettable that the child has come to use the fact that she has Turner syndrome as an excuse for not doing well in athletics and that she seems to have given up.
- The child once became deeply depressed after she was informed of the medical condition.
- The child is overly worried she might not be able to have her own baby.
- The child now feels negative about marriage.
- The child has become more worried than necessary (She has become too nervous about her constitution and overly sensitive about what she eats).

Fig. 2a  Questionnaire to Turner girls: By whom were you informed of the fact you are suffering from Turner syndrome?

Fig. 2b  Questionnaire to Turner girls: Who do you think would be an ideal person to inform you of the medical condition?

Fig. 2c  Questionnaire to Turner girls: When did you learn of your medical condition?
whether they should ever inform their children of it at all.

Although parents recognize the need to inform their children, in reality they are worried about when, by whom and how the children should be informed (Fig. 1b). Many parents actually talk about such worries with the other members of Wakaba’s Society (Fig. 1c). As shown in Fig. 1d, most parents seem to take informing their child positively, but there might be some bias such as the parents who responded to the questionnaire, being members of Wakaba’s Society, are positive about informing their child. As Table 1 indicates, some parents thought there were some bad aspects as well. Especially, probable infertility seems to affect and to make Turner girls nervous about

Table 2  Questionnaire to Turner girls: Please write down your experience if you have gone through any mental changes since being informed of the medical condition

<table>
<thead>
<tr>
<th>Age</th>
<th>Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>9 yr old</td>
<td>I was terribly shocked to find out that I have an illness.</td>
</tr>
<tr>
<td>9 yr old</td>
<td>I felt I was in for something terrible. I wished I had not known.</td>
</tr>
<tr>
<td>10 yr old</td>
<td>I was very much surprised.</td>
</tr>
<tr>
<td>12 yr old</td>
<td>It came as a slight shock.</td>
</tr>
<tr>
<td>12 yr old</td>
<td>I have become more determined.</td>
</tr>
<tr>
<td>17 yr old</td>
<td>I have come to deal with things more positively.</td>
</tr>
<tr>
<td>17 yr old</td>
<td>I have come to think more of what other people feel, and have found myself to be a kinder person than before.</td>
</tr>
<tr>
<td>18 yr old</td>
<td>I felt deeply depressed for a while.</td>
</tr>
<tr>
<td>19 yr old</td>
<td>I have tried hard to come to terms with myself.</td>
</tr>
<tr>
<td>20 yr old</td>
<td>I have lost confidence in my parents. I feel that I am imperfect as a female (She was informed of medical condition by her doctor).</td>
</tr>
</tbody>
</table>

Some answered that there was nothing particular to mention.

The age indicated above is when the Turner subject was informed of the medical condition.
relationships with the opposite sex.

**Questionnaire to Turner girls**

Turner girls had actually been told of their medical condition by either their parents or their doctor, the ratio being evenly divided. While a previous survey showed many doctors informing Turner subjects of their medical condition, it seems more parents are playing a role nowadays. Since many Turner girls ideally prefer to be informed of the medical condition by their parents, it is important that the parents by themselves must first understand Turner syndrome and then accept it.

Half of the Turner subjects surveyed knew that they were suffering from Turner syndrome by the time they had graduated from elementary school, but 36% did not know until they entered high school, or even later. This might be due to the current time and present circumstances, in which the respondents happened to be fairly grown-up. In the past, most Turner subjects received treatment without being informed of the medical condition, and they did not have any means of knowing about the medical condition even if they had wanted to. As to when would be the best time to be informed, the answers vary from some time in the upper grades of elementary school to senior high school. This might be due to different interpretations of the question by the individuals.

As Fig. 2 indicates, many Turner girls did not know anything about their predisposition or about why they had to go to the hospital until they were informed of their medical condition. They must have had a lot of anxiety and doubts. On the other hand, as Table 2 shows, since being informed of the medical condition they have gone through mental changes. The older the Turner subjects is, the more positive the attitude she seems to be. As is clear from the case of Turner woman who is 20 yr old, it would mean a lot for the Turner subjects to be informed of the medical condition at an appropriate age.

However free a Turner girl may feel about asking her doctor about health problems, it would be much harder for a patient to tell the doctor about worries. Parents and Turner girls talk about their worries and anxieties with fellow members. We have realized that a Turner subjects’ group like Wakaba’s Society can play a very important role since it offers the members good opportunities to find ways to solve their problems through supporting each other.

Many parents feel they would definitely like to inform their children of the medical condition, while the children prefer to be informed by their parents. However, since the Turner subjects and their parents are all in different situations environmentally, family-wise, patients age-wise, etc., there can never be a standard. Even if they get past the informing problem, it does not mean the end, but rather a new start in dealing with Turner syndrome.

Those who want to make contact with Wakaba’s Society, please access the following address.

http://www.club-turner.jp/wakaba/index.html