Acceptability of the health-related quality of life instrument EQ-5D-Y-5L among patients in child and adolescent psychiatric inpatient care

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Abstract

Aim: The generic EuroQol 5 Dimensions Youth 5 Level (EQ-5D-Y-5L) measures health-related quality of life among children from 8 years. Respondents report their health on five dimensions with five severity levels and rate their overall health on a visual analogue scale (EQ VAS). The aim of the study was to explore acceptability of the EQ-5D-Y-5L instrument among patients in child and adolescent psychiatric inpatient care.

Methods: A convenience sample of patients within a psychiatric inpatient care clinic in Region Stockholm, Sweden, was used. Follow-up questions were answered directly after filling in the EQ-5D-Y-5L. Conventional qualitative content analysis was chosen to analyse the open-ended questions on how they perceived answering the instrument.

Results: In total, 52 patients (83% girls), mean age 15.4 years (range 13-17), were included. Three themes emerged: generic content of the EQ-5D-Y-5L descriptive system; design and wording of the EQ-5D-Y-5L descriptive system and the EQ VAS; self-reporting health with the EQ-5D-Y-5L descriptive system and the EQ VAS.

Conclusion: The inclusion of physical health dimensions was perceived as positive, but some patients considered the descriptive system too generic. The results indicate that these patients in general could self-report their health in a meaningful way with the EQ-5D-Y-5L instrument.

Keywords
adolescents, EQ-5D-Y-5L, patients, psychiatric disorders, qualitative content analysis
1 | BACKGROUND

The EuroQol 5 Dimension Youth (EQ-5D-Y) is a generic Patient-Reported Outcome Measure (PROM), developed to measure Health-Related Quality of Life (HRQoL) among children from 8 years.1,2 The descriptive system of the EQ-5D-Y has five health dimensions: mobility, looking after myself, doing usual activities, having pain or discomfort and feeling worried, sad or unhappy. The version EuroQol 5 Dimensions Youth 3 Level (EQ-5D-Y-3L) with three severity levels, no problems, some problems and a lot of problems, has been tested in terms of feasibility, validity and reliability in general populations and patient populations of children and adolescents.3-6 The content of the EQ-5D-Y-3L compared to other generic PROMs has been investigated by interviewing children and their parents.7,8

A version of the instrument with five severity levels, EQ-5D-Y-5L, was developed in 2019 in an international collaboration between Germany, Sweden, UK and Spain, by interviewing the target population in each country to find suitable labels for the five severity levels.9 Employing a generic HRQoL instrument in a specific patient group facilitates comparisons of HRQoL across disease groups as well as with the general population.10

Using a new instrument or using an instrument in a new context requires testing of its psychometric properties.11,12 It has been more common to investigate HRQoL among children and adolescents with physical than psychiatric disorders. There are a few studies investigating HRQoL of children with mental disorders that compares the results with healthy controls.13

Testing the psychometric properties of the EQ-5D-Y-5L in different populations is also recommended by those developing the instrument.9 A comparison of the EQ-5D-Y-3L and the EQ-5D-Y-5L, regarding reliability and ceiling effects, has been conducted among Chinese patients with scoliosis.14 Åström et al15 employed the EQ-5D-Y-5L among patients in child and adolescent psychiatric inpatient care where convergent validity and feasibility were tested, leading to initial support of the use of the instrument in this context.

Beyond testing the psychometric properties of an instrument, it is also important to explore how the instrument succeeds in measuring outcomes that matter to patients, as well as patients’ understanding of the questions asked.10,16 For such purpose, qualitative methods can be applied, for example cognitive interviewing, think-aloud processes and comments to open-ended survey questions.7,8,17-22

During the same data collection reported in Åström et al,15 answers were collected on closed-ended and open-ended follow-up questions regarding what patients thought about the EQ-5D-Y-5L instrument. In the present study, we present the results from these follow-up questions. The aim of the present study was to explore acceptability of the EQ-5D-Y-5L instrument among patients in child and adolescent psychiatric inpatient care.

2 | METHODS

2.1 | Setting

Child and adolescent psychiatric specialist care in Sweden is provided to children and adolescents below 18 years in outpatient and inpatient care facilities.23 In Region Stockholm, the child and adolescent psychiatric inpatient care clinic includes an emergency department and inpatient wards. Around 400 patients are treated yearly within this inpatient care clinic.23

2.2 | Study participants and data collection

The inclusion criteria were to be 8 years or older, to have knowledge in Swedish language and having stayed overnight at the emergency department or admitted to the inpatient care clinic. Patients could be included from 8 years of age as the EQ-5D-Y-5L instrument is developed for self-completion from that age. Healthcare personnel assessed the condition of each patient who fulfilled the inclusion criteria before they were asked to participate, and patients who were assessed not to manage to participate were not asked.

All eligible patients and their parents received information about the study, both orally and printed information administered together with a form for written informed consent. Those consenting to participate formed the convenience sample. Data were collected through self-completion with paper and pencil in the presence of an interviewer (SK). If patients expressed the writing to be burdensome, the interviewer helped with writing. Data collection took place between January and April 2018.

The present study is part of a larger study assessing the EQ-5D-Y-5L instrument, the Strengths and Difficulties Questionnaire (SDQ) and a self-rated health question, those results are presented and discussed elsewhere.15 In addition, after completion of the EQ-5D-Y-5L, follow-up questions regarding patients’ thoughts about the EQ-5D-Y-5L were asked. The results regarding the follow-up questions are presented in the present study.

2.3 | The EQ-5D-Y-5L instrument

The EQ-5D-Y-5L instrument consists of the descriptive system with the five dimensions mobility, looking after myself, doing usual activities,
having pain or discomfort and feeling worried, sad or unhappy, and a visual analogue scale (EQ VAS) with a recall period of TODAY.7 Each dimension has five severity levels: no problems, little bit of problems, some problems, a lot of problems and cannot/extreme problems. On the EQ VAS, the respondents rate their overall current health between 0 (the worst imaginable health) and 100 (the best imaginable health).

Follow-up questions were formed to be completed by the patient directly after completing the EQ-5D-Y-5L. There were closed-ended and open-ended questions (Table 1). The answering options to the closed-ended questions were on a 5-point Likert-type scale. Open-ended questions were formed to solicit qualitative responses.

2.4 | Ethical considerations

Ethical approval was granted by the Regional Ethical Review Board, Stockholm, Sweden (Dnr: 2017/2491-32; 2018/245-32).

2.5 | Data analysis

Characteristics of the sample, answers to the closed-ended questions and percentage of responses to each open-ended question were examined by descriptive statistics. Conventional qualitative content analysis was chosen to analyse the open-ended questions. Initially, the open-ended questions were extracted to an Excel sheet, each open-ended question on a separate sheet according to the research questions. An inductive process was adopted; the answers were read repeatedly by the first author to get a sense of the responses and then read word by word to find core thoughts. The core thoughts were condensed (if needed) and labelled with a code, such as ‘feeling in the moment’.24 The codes were continually discussed among the authors. A constant comparison approach was used to categorise the data17,25; a code was compared with the rest of the data to induce analytical categories. The codes were first clustered into subcategories that share commonalities, and the subcategories arranged and re-arranged into broader, mutually exclusive categories to describe as many nuances of the data as possible.24 An initial theme emerged from each analysis. If a patient had not provided a response to an open-ended question, the empty space was not considered to provide a core thought and was excluded from the analyses. Also, if a patient had given a response such as ‘I don’t know’ that response was excluded from the analyses. The categorisation of data and development of themes were constantly discussed among the authors.

3 | RESULTS

3.1 | Sample characteristics

In total, 52 patients (83% girls), with a mean age of 15.4 years (range 13–17 years) completed the questionnaire. Just under three-quarters (73%) reported that they had had mental health difficulties over 12 months, and sample characteristics are presented elsewhere.15 The primary diagnoses were depression (29%); anxiety disorders (25%); bipolar affective disorder (12%); reaction to severe stress and adjustment disorders (12%). The majority (54%) had a neuropsychiatric and other co-morbidity, most often ADHD or autism spectrum disorder. For the open-ended questions, the response rate ranged between 54%-87% (Table 2).

3.2 | Results of the closed-ended questions

The distribution of response options to the closed-ended questions is presented in Table 3. Most of the patients (75%) found the EQ-5D-Y-5L dimensions very easy or easy to understand, and a majority (69%) answered that it was very easy or easy to find a suitable response alternative among the five severity levels. Regarding the EQ VAS, 55% found it very easy or easy to mark an X on the scale that showed their health and 14% answered that it was difficult. More than half (53%) of the respondents answered that the dimensions in the EQ-5D-Y-5L could describe their health in a very good or good way, while 18% answered bad. No one used the response option very difficult or bad, respectively, to any of the questions.

3.3 | Result of the content analysis

The content analysis revealed three themes: ‘generic content of the EQ-5D-Y-5L descriptive system and the EQ VAS’; ‘design and

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**TABLE 1** Follow-up questions to the EQ-5D-Y-5L instrument

| 1. How did you find it to fill in your answers to the questions? | a |
| 2. How easy/difficult was it for you to understand the questions? | b |
| 3a. In the questionnaire there were different areas that concern your health. They were ‘mobility’, ‘looking after myself’, ‘doing usual activities’, ‘having pain or discomfort’ and ‘feeling worried, sad or unhappy’. How good/bad do you think that you can describe your health (how your health is) with these areas? | c |
| 3b. Why? | d |
| 4. In the questionnaire there were even five different answer alternatives for each question; ‘no problems’, ‘little bit of problems’, ‘some problems’, ‘a lot of problems’ and ‘cannot’ or ‘not having pain/worried’, ‘a little pain/worried’, ‘some pain/worried’, ‘a lot pain/worried’ and ‘extreme pain/worried’. How easy/difficult was it for you to choose an alternative that is suitable to describe your health? | e |
| 5. Are there other things that you think are important to ask about your health (how your health is)? If yes, what? | f |
| 6. You also marked an ‘X’ on the scale that goes between 0-100. How easy/difficult was it for you to mark an ‘X’ on the scale that shows your health? | g |
| 7. What did you think when you marked the ‘X’ on the scale that goes from 0 to 100? | h |

a Open-ended question.
b Closed-ended question. Answering options: very easy; easy; neither easy nor difficult; difficult; very difficult.
c Closed-ended question. Answering options: very good; good; neither good nor bad; bad; very bad.
wording of the EQ-5D-Y-5L descriptive system and the EQ VAS; ‘self-reporting health with the EQ-5D-Y-5L descriptive system and the EQ VAS’ (Table 4).

### 3.3.1 Generic content of the EQ-5D-Y-5L descriptive system

This theme represents what the patients thought about the generic content of the EQ-5D-Y-5L instrument and consists of four categories: generic; the EQ-5D-Y-5L descriptive system is able to describe health; lacking questions specifically related to symptoms of a psychiatric disorder; and lacking questions about other psychological and psychosocial aspects.

Regarding the descriptive system, the categories include positive and negative attributes. The category generic includes the subcategories: captures broad health dimensions, and too generic to be able to describe health. The benefits of capturing broad health dimensions were reflected in the patients’ responses in terms of the relevance of including questions about physical function. The patients commented on how questions about mobility or ability to look after oneself can reveal the severity of the psychiatric disorder or how the symptoms of a psychiatric disorder can affect physical aspects of one’s health. One patient reflected upon the breadth of the questions and inclusion of physical aspects:

They [referring to the physical dimensions in the EQ-5D-Y-5L instrument] are good because they are things that are not asked very often – a side-effect of mental illness that is not spoken of.

16-year-old.

The subcategory too generic questions to be able to describe health includes responses where patients reported that many questions about physical aspects were included in the questionnaire or that the psychological aspects were not deeply explored in the instrument. One patient wrote about the instrument being too generic:

The psychological part was not really deeply touched upon. I am a human being who is seemingly self-controlled and rational, but everything can be chaos inside the head. That is why I am seldom physically affected unless it is a day I am fully paralysed, which happens rather seldom.

17-year-old.

The category, EQ-5D-Y-5L descriptive system is able to describe health, includes the subcategory nothing to add. When the patients were asked whether there are additional things that are important to be asked about regarding their health, many patients responded that they did not have anything to add or that the descriptive system was

### Table 2 Percentage (n) of respondents answering each open-ended question

| Question                                                                 | %    | n  |
|--------------------------------------------------------------------------|------|----|
| 1. How did you find it to fill in your answers to the questions?         | 86.5 | 45 |
| 3b. Why? (the follow-up question to: How good/bad do you think that you can describe your health (how your health is) with the EQ-5D-Y-5L dimensions?) | 69.2 | 36 |
| 5. Are there other things that you think are important to ask about your health? If yes, what? | 53.8 | 28 |
| 7. What did you think when you marked the X on the scale that goes from 0-100? | 82.7 | 43 |

### Table 3 Number of patients by response option, closed-ended question

| Question                                                                 | 1 | 2 | 3 | 4 | 5 | Missing |
|--------------------------------------------------------------------------|---|---|---|---|---|---------|
| 2. How easy/difficult was it for you to understand the questions?         | 22| 17| 11| 2 | 0 | 0       |
| 3a. In the questionnaire there were different areas that concern your health. They were ‘mobility’, ‘looking after myself’, ‘doing usual activities’, ‘having pain or discomfort’ and ‘feeling worried, sad or unhappy’. How good/bad do you think that you can describe your health (how your health is) with these areas? | 5 | 22| 15| 9 | 0 | 1       |
| 4. In the questionnaire there were even five different answer alternatives for each question; ‘no problems’, ‘little bit of problems’, ‘some problems’, ‘a lot of problems’ and ‘cannot’ or ‘not having pain/worried’, ‘a little pain/worried’, ‘some pain/worried’, ‘a lot pain/worried’ and ‘extreme pain/worried’. How easy/difficult was it for you to choose an alternative that is suitable to describe your health? | 12| 24| 11| 5 | 0 | 0       |
| 6. You also marked an ‘X’ on the scale that goes between 0-100. How easy/difficult was it for you to mark an ‘X’ on the scale that shows your health? | 14| 14| 16| 7 | 0 | 1       |

*Closed-ended question. Answering options: (1) very easy; (2) easy; (3) neither easy nor difficult; (4) difficult; (5) very difficult.

*Closed-ended question. Answering options: (1) very good; (2) good; (3) neither good nor bad; (4) bad; (5) very bad.
adequate. The category lacking questions specifically related to symptoms of a psychiatric disorder includes the following subcategories: affective symptoms; cognitive symptoms; other bodily impact such as appetite and sleep. In the subcategory affective symptoms, the most frequently reported aspects were mood, mood swings, anger and suicidal ideation or plans. The category lacking other psychological and psychosocial aspects includes the subcategories sense of control, psychological capital and relationships. The subcategory psychological capital contained aspects of feeling hope or one’s ability to focus on the positive aspects in life.

3.3.2  |  Design and wording of the EQ-5D-Y-5L descriptive system and the EQ VAS

This theme consists of two categories: simple design and wording of the descriptive system; ambiguous formulation and wide scale in the EQ VAS. The category regarding the descriptive system includes the subcategories simple design and lacking precision. Many patients found the design to be simple. This was seen positive, as the instrument was perceived as being fast to complete, but also negative as it was perceived as too simple. Lacking precision was described as the content in each dimension being too wide or ambiguous. One patient reflected upon the dimension looking after myself and noted that this dimension covers a larger content than only washing and dressing, such as sleep, hygiene and eating nutritious food.

The category ambiguous formulation and wide scale in the EQ VAS includes the following subcategories: ambiguous formulation; childish; wide scale. Regarding the perceived ambiguous formulation, some patients commented they were not sure what was meant by the concept health. One patient reflected upon the subjectivity, as for one person a score of 50 on the EQ VAS may be a sign of good health, whereas for another the same score may be a sign for poor health. One patient found filling in the EQ VAS somewhat childish, while another found the large scale facilitating to express feelings properly. One patient expressed the following about the EQ VAS:

…it was, however, comfortable with such a wide scale, from 0-100, not from 0-10. There was more room to express the feeling.

17-year-old.

3.3.3  |  Self-reporting health with the EQ-5D-Y-5L descriptive system and the EQ VAS

This theme represents what the patients wrote about the thoughts they had when completing the EQ-5D-Y-5L descriptive system. The theme has six categories: easy and good; easy and good with uncertainty; difficulty in reflecting one’s health with the EQ-5D-Y-5L descriptive system; self-perception in self-rating. The two EQ VAS related categories are: EQ VAS is filled in with thoughts about different emotional states in time; EQ VAS is filled in with thoughts about different dimensions of health.

The category easy and good includes the following subcategories: being easy to complete; being not bothersome to complete; being generally good and subjective. For instance, one younger patient wrote that the instrument was easy to fill in because the patient’s mother was present, and the patient could turn to her for guidance. A few patients signalled uncertainty by describing the instrument with positive adjectives, such as good, but adding a question mark. The category difficulty to reflect one’s health with the EQ-5D-Y-5L...
The adult version of the instrument in previous studies.17,20,21,26

System described their health badly; similar results have been found for the EQ-5D-Y-5L dimensions and not solely in the dimension feeling worried, sad or unhappy.15 On the other hand, some patients reported that the EQ-5D-Y-5L was lacking questions specifically related to symptoms of a psychiatric disorder or other psychological and psychosocial aspects. These contradicting findings suggest that in this patient group, a generic instrument preferably should be employed alongside a condition-specific instrument to cover both the wider aspects of health and the condition-specific aspects that were mentioned by the patients.

In the second theme, design and wording of the EQ-5D-Y-5L descriptive system and the EQ VAS, the simple design of the EQ-5D-Y-5L was seen as both positive and negative due to its shortness. In a study by Crawford et al,28 an expert group of adult mental health service users with psychosis and mood disorders reported concerns over the EQ-5D as it was perceived to be too short to assess the complex outcomes that it was developed to be measuring. This was also mentioned in the present study. That some patients found the EQ VAS to be somewhat childish while others found the scale enabling to express feelings properly could be related to the age and maturity of the patient.

The third theme, self-reporting health with the EQ-5D-Y-5L descriptive system and the EQ VAS, covers aspects on how the patients experienced completion of a self-reported, generic instrument. Many reported that the completion was easy, which is in line with previous studies about the feasibility of the EQ-5D-Y-3L instrument.3-6 There were only a few patients who reported difficulties in reflecting their health with the EQ-5D-Y-5L.

Some patients described self-perception as a support when answering a questionnaire, whereas only a few reported difficulties when describing their health. Awad et al26 have previously discussed the use of PROMs among patients with mental disorders and concluded that patients can provide reliable assessments of their health. We have no reason to conclude the opposite in our study. However, a few patients found the completion difficult or did not want to participate, assumingly due to the severity of their condition. Therefore, other modes of administration, such as proxy report from a parent, may be considered as an alternative for some of the patients in this context.

4 | DISCUSSION

In the present study, we explored acceptability of the EQ-5D-Y-5L instrument among patients in psychiatric inpatient care by asking closed-ended and open-ended questions. In total, 52 patients, aged 13-17 years, within a psychiatric inpatient care clinic in Region Stockholm, Sweden, participated.

The majority of the participants found the EQ-5D-Y-5L to be an understandable instrument to complete and that the response options were suitable to describe their health, which was reflected by their responses to the closed-ended questions. This finding was also supported by the results of no missing values for the EQ-5D-Y-5L dimensions and one missing value for the EQ VAS, in the same sample, presented by Åström et al.15 However, some patients reported that the descriptive system described their health badly; similar results have been found for the adult version of the instrument in previous studies.17,20,21,26

Three themes emerged from the content analysis. The content of the first theme, generic content of the EQ-5D-Y-5L descriptive system, has also been reflected in previous studies. In a study by Wolstenholme et al,8 children and their parents in the general population found the EQ-5D-Y-3L to be superior compared to the generic Child Health Utility 9 Dimensions (CHU 9D) due to its better suitability across ages and conditions, and the benefits of fewer questions. In a study by Bray et al,7 young wheelchair users and their parents described the EQ-5D-Y-3L to capture adequate health dimensions to some degree. However, in both studies, the participants reported issues concerning the sensitivity of the EQ-5D-Y-3L.7,8

In the present study, patients in psychiatric inpatient care found the inclusion of physical dimensions relevant to describe their health. A similar finding was reported by Brazier et al,27 where physical health was found to be one of seven core dimensions to have an impact on HRQoL described by adults with psychiatric disorders. This finding was also in line with how the same sample of patients as in the present study, reported problems across all EQ-5D-Y-5L dimensions and not solely in the dimension feeling worried, sad or unhappy.15 On the other hand, some patients reported that the EQ-5D-Y-5L was lacking questions specifically related to symptoms of a psychiatric disorder or other psychological and psychosocial aspects. These contradicting findings suggest that in this patient group, a generic instrument preferably should be employed alongside a condition-specific instrument to cover both the wider aspects of health and the condition-specific aspects that were mentioned by the patients.

When a lot and so many emotions are pressed in the head at the same time it is difficult to grade and assess well-being out of a few statements and scales.

17-year-old.

The category self-perception in self-rating includes the subcategories self-perception as a support in completion and difficulty with self-reporting. Self-perception as a support was described by patients as an ability to reliably reflect upon the difficulties one experiences in one’s health situation or by listing all symptoms and functional limitations as a sign of being aware of their health-related difficulties. Those reporting difficulty with self-reporting reflected upon their insufficient ability to describe their own health.

Two categories regarding the generic nature of the EQ VAS evolved. The category EQ VAS is filled in with thoughts about different emotional states in time which includes the following subcategories: comparison with previous well-being; immediate mood; mood today; well-being without further specification; general mood. Among these, the patients most often reported that they answered the EQ VAS by thinking about their immediate mood. The category EQ VAS included thoughts about different dimensions of health and comprises the following subcategories: symptoms and functional ability; health as a physical and mental entity; the descriptive system of the EQ-5D-Y-5L; social aspects. One patient reported thinking about symptoms and social situation when completing the EQ VAS and this was the reflection:

I feel safe, but I sleep badly constantly and that makes me worried.

16-year-old.
The patients provided a variety of thoughts when filling in the EQ VAS. Many reported thinking about an immediate mood. This is in line with the study by Feng et al., who concluded that the EQ VAS may measure something that has a very close proximity to the patients and thus measures something different than the descriptive system.

Our study had several limitations. Alternative ways of collecting data, for example by in-depth interviews, could have been considered to investigate acceptability of the instrument. However, in this setting of psychiatric inpatient care, it might have been too burdensome for the patients. Those assessed by healthcare personnel not being able to manage to participate in the study were not asked to participate, due to their vulnerable situation. This may influence the transferability of the results of the present study to other contexts. The presence of an interviewer might have led to patients acting less attentively and giving a socially desirable response, such as reporting the EQ-5D-Y-5L as a good and easy instrument. Most patients completed the questionnaire with only the interviewer present. However, for those also having a caregiver present, we cannot assess how or in what way that might have influenced the results.

Compared to other more comprehensive generic PROMs, the EQ-5D-Y-5L may have advantages for these patients as it may be burdensome to fill in lengthy instruments. The generic nature of the instrument and the inclusion of physical health dimensions for this patient group were seen as positive. However, some patients considered it being too generic. Future studies need to explore acceptability of the EQ-5D-Y-5L in other disease groups.

5 | CONCLUSION

This study sheds light on the possibility to employ a generic self-reported HRQoL instrument among patients in psychiatric inpatient care. The results indicate that these patients in general could self-report their health in a meaningful way with the EQ-5D-Y-5L instrument. The generic nature of the instrument and the inclusion of physical health dimensions for this patient group were seen as positive. However, some patients considered it being too generic. Future studies need to explore acceptability of the EQ-5D-Y-5L in other disease groups.

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CONFLICT OF INTEREST

The authors, MÅ and KB, are both members of the EuroQol Group. The other authors have no conflicts of interest.

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