Assessment of parents’ concerns and evaluation of outcomes
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Abstract

Background Clinical and service evaluation often fails to accommodate sufficiently to parental perspectives and priorities concerning health interventions. Although parent satisfaction questionnaires are widely used, these assess issues chosen by the researcher. Quality of life research methods, however, can assess individual priorities.

Methods A Schedule for Evaluation of Quality of Life was adapted to record the nature, and relative importance of parental concerns about their child before child psychiatric hospital admission. Level of concern or worry was assessed pre- and post-admission, and at 1 year follow-up, with a waiting-list control. Data were analysed qualitatively and quantitatively for individuals and groups of cases.

Results The adapted instrument was feasible and clinically useful. It did not show repeated measurement effects but was sensitive to the effects of intervention (hospital admission). Effects (reduction in levels of concern) remained evident at 1 year follow-up.

Conclusion The instrument is brief, non-intrusive, and sensitive to change. It has utility for clinical case evaluation. It may complement satisfaction questionnaires, and has advantages over rating scales for the evaluation of treatment outcomes.

Keywords: evaluation, outcome, parent satisfaction, quality of life

Introduction

Evaluating clinical change is of increasing importance in the National Health Service, for clinical, research and evaluation, and organizational purposes.

It is widely accepted that evaluation of change with complex problems, as in child health, requires multiple measures of change. However, even experienced researchers in the field sometimes neglect the need not only for multiple measures, but also for multiple perspectives in evaluating change. Thus Hunter et al., concluded a review of outcome measures in child mental health with a plea for ‘a single tool that meets all our criteria [which] would significantly aid the routine measurement [of] clinical outcomes’. This search for more comprehensive assessment tools fails to address the need for evaluation of service outcomes to be responsive to the different concerns and perspectives of various stakeholders in child health services. In child health evaluation, it is common to sample parental perceptions by including parent-report data, or parent satisfaction indices. These usually take the form of questionnaires asking about predetermined issues selected by researchers. Such questionnaires do not enquire as to what specific issues are actually of most concern to individual parents. However, it is noteworthy that in one study the item showing greatest correlation with overall satisfaction asked whether the service had ‘helped deal with the problems’.

Thus systematic enquiry about the actual nature and specific content of parental concerns (and whether they are ameliorated) has been neglected, possibly because of the lack of a suitable instrument.

Assessing change as a consequence of intervention in specialist services with children and adolescents with complex problems is difficult. Such services frequently are attempting to mitigate the effects of multiple chronic problems, and simple improvement in presenting symptomatology is often either difficult to achieve or difficult to demonstrate. Individual measures of parents’ or others’ perceptions of change, if sufficiently sensitive, may therefore be valuable for both clinical and service evaluation.

The Schedule for the Evaluation of Individual Quality of Life (Direct Weighting procedure) (SEIQOL-DW) was developed to provide a measure of quality of life that reflected the issues most important to the individual. The SEIQOL-DW allows respondents to nominate the five areas most important to their quality of life, and rate their level of satisfaction with each. Using a simple coloured disc, like a pie-chart, the weighting or importance of each area of life is then assessed so that the total weighting for all five areas is 1.00. (For example, marital life might be weighted as important, but rated as currently unsatisfactory.) Status or satisfaction ratings are made on a
visual analogue scale 0–100. A total weighted index may be calculated as the sum of weightings multiplied by ratings, and may range from zero to 100. Its strengths as a research tool include: short administrative time, reliability,7 acceptability to informants and ability to quantify information, which at the same time reflects the specific concerns of the individual. It also has strengths as a clinical tool: its clear relevance to the individual patient, its brevity, minimal training required, and the information it gives the clinician about what issues are of most current importance to the patient. The individualized nature of this assessment contrasts with brief standardized tools, such as the HONOSCA,8 which may not be used in busy clinical practice unless they directly help the clinician’s work with the patient.9

The present paper describes the adaptation of the SEIQOL-DW for use as an individualized assessment of the nature, importance and degree of parental concern about their child’s difficulties and the impact of their child’s development on the family. We also demonstrate the sensitivity of this measure to change over time and its resistance to repeated measurement effects.

Service context
This measure was developed as part of an outcome evaluation study of the effectiveness of admission to three 10- to 12-bedded in-patient units, of a supra-regional psychiatry service for children and adolescents with learning disability. One unit admits children as well as adolescents with severe disabilities. There is one open and one low-secure adolescent unit. Young people are admitted with a wide and complex range of presenting problems, including epilepsy, severe emotional and conduct problems, pervasive developmental disorders, mood disorders, sequelae of sexual abuse, and fire setting. Lengths of admission are very varied, from 2 to 48 weeks for admissions to the children’s disability unit, and from 4 to 60 weeks for the adolescent units.

Methods
Design and sample
Data were gathered for children admitted during a 2 year period from April 1997, during which there were 70 admissions to the child and disability unit, and 35 admissions to the adolescent units. Data for parents or carers were collected after referral before admission, at 2 weeks post-discharge, and at 1 year follow-up. When admission was delayed after referral (e.g. because of bed shortage) reassessment was conducted after 6 weeks. This provided a small sample of ‘waiting-list comparison’ data. A separate waiting list or comparison treatment control group was not possible for this study. Of these 105 admissions, parents or primary carers of 73 young people were available and agreed to participate in the study. (Henceforward we use the term parents for simplicity.) For pragmatic reasons, interviews were usually possible with the mother only (in one case with the father only) and maternal data only have been included therefore for the 16 cases where both parents were available. At the time of analysis, data were also available from 44 parents at 2 weeks post-discharge, and 15 parents at 1 year follow-up. (Seven parents declined to repeat assessment post-discharge; 22 young people had yet to be discharged.)

Procedures and analysis
To adapt the SEIQOL-DW to assess change in parents’ concerns about their children, a number of modifications were required to the procedure for administration. Our focus was the nature of parent concerns about their child, whether to do with health, education, relationships or future development and independence, in the context of probable admission to a specialized child psychiatric unit. We wished to preserve the instrument’s ability to allow individuals to identify the issues of most concern to them, although changing the focus from quality of life to ‘problem’ issues or areas of difficulty (which might or might not be addressed by the hospital admission). The administration of SEIQOL-DW was therefore altered as follows.

The SEIQOL-DW is administered in a standardized semistructured interview in three steps:5,10 elicit concerns; determine ratings of level of concern; determine weightings for the importance of each concern. For this adaptation, the three steps were: eliciting concerns about the child and their impact on the family; determining weightings (relative importance of each concern) by use of the coloured disc or pie chart; determining ratings of levels of concern (‘worry’).

To elicit concerns, parents were asked to say ‘what are the five most important concerns for you about [their child]. These may be about [the child], their problems, or the effects these are having on your life.’ In contrast to the SEIQOL-DW, where prompts are only given if ‘absolutely necessary’, pilot work indicated that parents needed some initial prompt to enable them to think sufficiently widely about possible concerns. The initial prompt drew attention to general issues such as their child’s health, concern about effects on the family, relationships, education or their future.

We also found it helpful to determine the weightings (relative importance of each concern) second, before rating levels of concern. In SEIQOL-DW respondents are asked to rate level of satisfaction with each area of life from ‘worst possible’ to ‘best possible’. In this adapted schedule, parents were asked to rate how worried they were about each concern on a 10 cm visual analogue scale from zero ‘not worried at all’ to 100 ‘as worried as could possibly be’. This measure is described as the level of concern.

Administration time was short, taking between 10 and 30 min.
For analysis we subsequently ranked the concerns in order of weighted importance given by the parent. It was then possible to summarize data for levels of concern (degree of worry 0–100) for the whole sample for issues of greatest importance, second, third, fourth and least importance.

To evaluate change, we asked parents to reassess their current level of concern on each of their five original concerns as expressed at initial assessment. This represents a further modification of the SEIQOL procedure to enable us to make comparisons before and after a health intervention. However, if desired it would also be possible to assess new issues of concern and their relative importance, after intervention.

Comparisons between preadmission, waiting list assessment, post-discharge, and follow-up data were made using t-tests for paired samples.

Results

A primary issue for any clinical assessment tool is acceptability to users. The present adapted schedule manifested adequate acceptability in this study. Parents completed the adapted schedule followed by a much lengthier questionnaire and a request to gather frequency data on behavioural difficulties with their child as part of a wider outcome study. From informal information collected, we believe that the seven parents who declined to repeat the assessment after discharge were put off by these other components of the study rather than by features of the adapted schedule. More than one parent found the collection of frequency data on behavioural difficulties time consuming and irksome, and did not take part after discharge as a result.

Used as part of routine pre-admission assessment, without other questionnaires, this adapted schedule often appears to help parents clarify and focus their own concerns before preadmission meetings with professionals.

This may be particularly helpful where children present carers with a number of difficulties at different levels of complexity. In one example the mother of an autistic young man with specific phobias, major social difficulties and epilepsy found the assessment of parental concerns helped her to recall, summarize and prioritize her concerns, and present these to the clinical team before admission.

It also helps clarify for clinicians any discrepancies between clinician and parental priorities during assessment. Discrepancies may occur between the priorities of the referrer, the parents and the clinical team. In one example, a 16-year-old autistic adolescent was referred primarily with a view to developing a management programme for a range of difficult and aggressive behaviours. Maternal priorities, however, focused particularly around weight loss and reluctance to eat, and her refusal to attend school. The clinical team addressed food intake initially, followed by programmes for her verbal and physical aggression. Education was still an issue at the time of discharge because the team had not yet secured the support required for this challenging young woman within the college placement that had been identified.

Often, awareness of discrepancies between referrer’s and parents’ perspectives helped the clinical team become alert to the variety of priorities, and integrate these into a plan of treatment. One 11-year-old boy was referred for assessment of behaviour thought to be linked to epilepsy. Epilepsy was not the parental priority; however, Maternal priorities were (in order of importance): social difficulties with peers; behavioural outbursts; soiling; epilepsy control; his future care. The team was able to incorporate these issues into the treatment programme with some success. The referrer’s aims of admission were achieved. The inclusion of these other issues was also commented on favourably by the referrer after discharge.

The adapted schedule is feasible to use in everyday clinical settings, although it took longer than the 5–10 min quoted for the SEIQOL-DW.5

Results for one parent (Figure 1) illustrate how the importance of concerns is assessed, and also what changes took place by the time of discharge in the level of concern about each of these. As commonly occurred, parental levels of concern were greatly eased about three concerns, including the two most important concerns, although levels of concern rose about issues that were not initially major worries. In this example, with concerns about epilepsy, bowel function and sleeping pattern addressed by the admission, the parent’s concerns became more focused on other unresolved issues – in this case, a hip problem, and eating patterns. The instrument may therefore prove useful as part of clinical evaluation of progress in individual cases.

The range of concerns raised by this sample of parents is illustrated in Table 1. The frequency of developmental problems in this sample (all children had some general or specific learning disability) is expected. The range of other concerns reflects many of the presenting symptoms requiring treatment in this sample, such as aggression, relationship difficulties or sexualized behaviour. A substantial number of concerns were about issues such as educational placement and future care, which could be addressed, but not resolved, by a health care admission.

One parent’s most important concern was that her 15-year-old son was missing much of his education through playing truant, and through temporary exclusions. He had been referred because of increasingly dangerous, unpredictable aggression. This aggression was ameliorated during admission through bereavement counselling and medication for an epileptic component to his behaviour. In this case, a new school placement was identified, and attendance improved. However, in other cases improved educational arrangements were not always possible. Parents’ anxieties about future health or social support were sometimes increased after an admission that clarified the nature and degree of their child’s difficulties.

Vulnerability to the effects of repeated testing was explored by reassessment after 6 weeks for a small number of children.
who were still awaiting admission. Mean levels of worry about initial concerns showed no significant change after this period (Table 2), although there was a non-significant tendency for some levels of concern to fall slightly. This is important as with large samples it is possible that significant amelioration in levels of concern might be demonstrated in studies using repeated measures, without active interventions. This is a commonly neglected aspect in outcome evaluation studies, although other child mental health assessment tools do show apparent improvement merely on retesting.\(^{11}\)

Sensitivity to change after intervention was tested by comparing levels of worry about initial concerns pre- and post-admission (Figure 2). Significant reductions occurred in mean levels of worry about the most important concerns. This is evidence that the adapted schedule is appropriately sensitive to changes as a consequence of clinical intervention. Interestingly, when levels of concern at 1 year after discharge were compared against pre-admission levels of concern, much of the improvement found at discharge was maintained (Table 3).

**Discussion**

This adaptation of the SEIQOL-DW to provide a schedule for the evaluation of individual parental concerns appears to have

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**Table 1** The distribution of types of parent or carer concerns; number of people (n = 73) mentioning each concern as one or more of their five concerns

<table>
<thead>
<tr>
<th>Types of concern</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Development problems (e.g. problems with development of independent living skills, language and communication problems)</td>
<td>34</td>
</tr>
<tr>
<td>Aggression</td>
<td>27</td>
</tr>
<tr>
<td>Future care (e.g. worries about who will look after him/her in future)</td>
<td>22</td>
</tr>
<tr>
<td>Mood and mental health worries</td>
<td>17</td>
</tr>
<tr>
<td>Family relationships</td>
<td>16</td>
</tr>
<tr>
<td>General physical health (e.g. problems with health and medication not specified in other categories)</td>
<td>16</td>
</tr>
<tr>
<td>Educational placement (e.g. education placement needs not being met)</td>
<td>15</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>12</td>
</tr>
<tr>
<td>Incontinence</td>
<td>9</td>
</tr>
<tr>
<td>Non-compliance</td>
<td>8</td>
</tr>
<tr>
<td>Sexualized behaviour</td>
<td>7</td>
</tr>
<tr>
<td>Hyperactivity</td>
<td>7</td>
</tr>
<tr>
<td>Sleep pattern</td>
<td>7</td>
</tr>
<tr>
<td>Inappropriate behaviour (e.g. screaming, screeching, shouting)</td>
<td>6</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>5</td>
</tr>
<tr>
<td>Self-injurious behaviour</td>
<td>5</td>
</tr>
<tr>
<td>Obsessive behaviour</td>
<td>4</td>
</tr>
<tr>
<td>Criminal and related behaviour</td>
<td>4</td>
</tr>
<tr>
<td>Fire setting</td>
<td>2</td>
</tr>
</tbody>
</table>

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**Table 2** Pre-admission waiting list sample: control for repeated measurement effects after six weeks; results for each of five ranked concerns (1 indicates greatest concern), paired sample t-test (n = 11)

<table>
<thead>
<tr>
<th>Ranked concern</th>
<th>Mean level of concern (0–100)*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>At referral</td>
</tr>
<tr>
<td>1</td>
<td>91.8 (3.0)</td>
</tr>
<tr>
<td>2</td>
<td>90.0 (4.5)</td>
</tr>
<tr>
<td>3</td>
<td>77.1 (6.5)</td>
</tr>
<tr>
<td>4</td>
<td>86.3 (6.0)</td>
</tr>
<tr>
<td>5</td>
<td>52.7 (8.8)</td>
</tr>
<tr>
<td>Total weighted index</td>
<td>84.4 (3.2)</td>
</tr>
</tbody>
</table>

*Standard error given in parentheses.
both potential clinical and research utility. The approach provided by the SEIQOL-DW when adapted in this manner has important strengths. The adapted schedule is capable of identifying issues important to individuals without the imposition of clinician or researcher constructs. In addition to this advantage over global rating scales (which have recently been advocated for the evaluation of child mental health outcomes\textsuperscript{12}), this method offers greater specificity and sensitivity of measurement. It is flexible: the approach could be extended easily to a variety of purposes; for example, to compare conflicting priorities – between family members, between families and professional or between internal and external agencies. It has clinical utility: we are using it to help clarify parental concerns, expectations and priorities as part of pre-admission planning. It is brief to administer, is non-intrusive, has face validity and individual relevance to the respondent,

\begin{table}[h]
\centering
\begin{tabular}{|l|c|c|c|}
\hline
Ranked concern & Pre-admission & Post-discharge & 1 year post-discharge & Significance pre-admission vs 1 year post discharge \\
\hline
1 & 83.7 (6.5) & 57.3 (7.7) & 49.3 (9.0) & < 0.01 \\
2 & 79.3 (6.2) & 63.3 (6.9) & 54.0 (7.9) & 0.03 \\
3 & 79.0 (4.5) & 56.7 (7.4) & 49.9 (8.9) & < 0.01 \\
4 & 74.3 (5.9) & 56.0 (6.1) & 46.0 (8.8) & 0.02 \\
5 & 60.4 (8.5) & 55.4 (10.8) & 56.2 (11.4) & 0.78 \\
Total weighted index & 79.1 (3.9) & 57.6 (5.5) & 49.7 (6.3) & < 0.01 \\
\hline
\end{tabular}
\caption{Mean level of concern (0–100) at pre-admission (black columns) and post-discharge (white columns). Results shown for each of five concerns (ranked importance, 1 indicates greatest), and total weighted index. Changes are significant for weighted index and ranked concerns 1–4. (Paired sample \textit{t}-test, probability levels shown; \(n = 44\)).}
\end{table}

\begin{table}[h]
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\begin{tabular}{|l|c|c|c|}
\hline
Table 3 One year follow-up data: results for each of five ranked concerns (1 indicates greatest concern), paired sample \textit{t}-test (\(n = 15\)) & & & \\
\hline
Mean level of concern (0–100)* & Pre-admission & Post-discharge & 1 year post-discharge & Significance pre-admission vs 1 year post discharge \\
\hline
Ranked concern & & & & \\
1 & 83.7 (6.5) & 57.3 (7.7) & 49.3 (9.0) & < 0.01 \\
2 & 79.3 (6.2) & 63.3 (6.9) & 54.0 (7.9) & 0.03 \\
3 & 79.0 (4.5) & 56.7 (7.4) & 49.9 (8.9) & < 0.01 \\
4 & 74.3 (5.9) & 56.0 (6.1) & 46.0 (8.8) & 0.02 \\
5 & 60.4 (8.5) & 55.4 (10.8) & 56.2 (11.4) & 0.78 \\
Total weighted index & 79.1 (3.9) & 57.6 (5.5) & 49.7 (6.3) & < 0.01 \\
\hline
\end{tabular}
\caption{One year follow-up data: results for each of five ranked concerns (1 indicates greatest concern), paired sample \textit{t}-test (\(n = 15\)).}
\end{table}

\*Standard error given in parentheses.
and requires little training. The disk and manual for SEIQOL\textsuperscript{10} are inexpensive. The original has evidence of reliability.\textsuperscript{7} The adapted instrument is sensitive to intervention, but appears relatively insensitive to repeated measures effects. It may be used to assess change in either a quantitative or a qualitative fashion. The instrument does require an initial face-to-face interview, although reassessment of levels of concern alone has proved feasible by post where post-discharge interview has not been possible. Under what circumstances it may be possible to use this adapted instrument to assess the concerns and priorities of children themselves remains to be demonstrated, but we are currently assessing further modifications to allow its use with adolescents who have both emotional and behavioural difficulties and significant learning disabilities. Meanwhile, this instrument is recommended for further validation as an instrument for assessing parents’ concerns and priorities, and for assessing parents’ perceptions of change.

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**References**


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