

The Generic Lifestyle Assessment Questionnaire

LAQ-G

CHAPTER 2

METHODS: QUESTIONNAIRE DEVELOPMENT

Item selection, reduction and the creation of response options

A Lifestyle Assessment Questionnaire (LAQ-CP), which measured the impact of childhood cerebral palsy, has been described previously [1]. It was constructed for children with cerebral palsy, specifically for use in the North of England Collaborative Cerebral Palsy Survey [2, 3]. We were familiar with the questionnaire and knew that parents found it straightforward to complete, and that clinical teams understood what the results meant; that it performed well as an objective and discriminative tool and yielded reliable results, which could be expressed and mapped on to health domains contained within the original International Classification ICDH. We also knew that it was easy to use with the survey register.

The disadvantage was that the LAQ-CP was disease specific (for cerebral palsy) and as such focused disproportionately on areas such as mobility, physical independence and use of clinical services. Some adaptation was therefore going to be necessary to make it appropriate for generic use.

For the new measure, the general format of the LAQ-CP was retained, but additional items reflecting a child's social relationships, behaviour, leisure activities, play and communication were required, and some of the original items needed to be removed to allow a final instrument of appropriate length. Although a primary aim of the research was to develop a tool for use by clinicians with special needs registers, it was important to include issues which both disabled children and their parents considered important. To assist in the process of item selection and generation, four approaches were used:

- the views of parents of children with disabling conditions were obtained by consulting two surveys of families caring for a disabled child [4, 5]. Both were conducted by the Social Policy Research Unit in York in collaboration with the Family Fund, which is a charitable organisation providing financial assistance to children with disabilities [6]. The surveys sought to explore parental perceptions about their own and their children's unmet needs. Parents felt that the most important problems for the children concerned independence, learning and social relationships. The most important problems for parents themselves concerned financial resources, behaviour problems in the child, care burden and social needs. Information provided by these surveys, as well as direct consultation with the Social Policy Research team,

resulted in the generation of a number of new items and the re-phrasing or de-selection of some established ones from the LAQ-CP.

- a review of relevant literature up to and including 1996 publications. Databases which were searched included Medline, Embase and CINAHL. “Grey literature” was explored following recommendations by colleagues and experts. Certain themes occurred regularly in the literature: issues of mobility, ability to leave the house, self-help skills, schooling, need for and use of medical services, the presence of symptoms (especially epilepsy and pain), restriction of leisure activities and factors pertaining to the family in terms of reduced income, increased care burden and effects on parental employment.
- the views of specialists. On the basis of the above two exercises, a list of approximately seventy possible items was drafted – aimed at children aged 5 to 7 - and presented to professionals representing health service research, social sciences, health economics, community paediatrics, learning disability, paediatric oncology, child mental health, developmental paediatrics and special needs education. These professionals were asked to comment on the items, whether they were perceived to be relevant and appropriate, and whether any particular aspect of disability had been missed.
- taking account of all above information, a small working group consisting of five professionals achieved a consensus view on 66 items to be included in a provisional generic Lifestyle Assessment Questionnaire (LAQ-G).

Questions focussed on a number of childhood experiences and sought to capture what the child “does do” on an everyday basis, not what they “can do” if pushed. The impact on parents and siblings in terms of employment, finances, travel, care burden and stress was also explored. Responses indicated either the frequency of a certain event occurring within a specific time period (over the last week, month or year) or the degree to which something was a problem (none, mild, moderate, severe). Parents were asked to circle one reply in a set, which contained three, four or five response options. For each question, scores from 0 to 4 were assigned for each point on the response set. The lowest score was always 0 and denoted “no problem”. The highest score was always 4. Intermediate scores depended on the number of possible responses (2; 1 and 2; or 1,2 and 3 for three, four and five response options respectively).

The pilot study

The provisional 66 item LAQ-G was piloted with the parents of 16 children (nine with disability and seven non-disabled controls) in the district of Northumberland. Parents were asked to complete the LAQ-G and their responses scored as outlined below. Scores were compared between parents of disabled and non-disabled children. To assess test-retest and inter-reporter

reliability, the same parents of three children (two cases and one control) completed a second LAQ-G after four to six weeks, and for three other children (two cases and one control) both parents completed the LAQ-G. In addition, five children (three cases and two controls) were observed by myself, from waking in the morning in their own home to leaving school in the afternoon, and an additional LAQ-G was completed by myself on these children in order to confirm the accuracy of parental reports. One child was observed simultaneously by a second researcher in order to test my own reliability.

Results from this pilot study showed a significant difference in mean item score for six out of seven case/control pairs, with no significant difference between test/re-test, inter-reporter or inter-observer completions, confirming that the LAQ -G appeared to discriminate between children with and without disability, and that parents of children with a range of difficulties accurately reported the impact of their child's disability, and were consistent over a short time-interval in these reports. Parents reported that questionnaire completion took fifteen to twenty minutes. Their comments on the questionnaire were encouraged.

On the basis of the pilot study and parental comments, some questions were re-worded, and items which were highly correlated (Kendall's correlation of 0.8 or more) and conceptually related were removed. The resulting LAQ-G had 53 items, contained within 45 questions.

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