

The Generic Lifestyle Assessment Questionnaire

LAQ-G

CHAPTER 5:

DISCUSSION

Summary of the findings

Measuring participation is important for a number of reasons: it allows comparisons to be drawn between various “levels” of disability and their consequences in different geographical or other environmental settings, and may assist in evaluating the outcomes of interventions or treatments. At a practical level, many health districts hold registers of children with disabilities or long term health conditions, and including a measure participation improves the information on such registers, both from an individual and from a public health perspective.

In order to measure participation, a Lifestyle Assessment Questionnaire designed for children with cerebral palsy (LAQ-CP) was adapted and piloted, resulting in a generic instrument LAQ-G, suitable for children with a range of disabilities.

The LAQ-G was completed by parents of children with and without known disability. The sample was selected to have a reasonable number of children with common disabling conditions found in a typical health district in the UK, and is therefore not representative of the population prevalence. Initial field-testing had shown that the LAQ-G discriminated between children with or without disability, was stable over time and had acceptable levels of inter-reporter reliability. A domain-based representation of participation was created by the application of a non-parametric statistical technique (Multi-dimensional Scaling MDS) to parental responses. This provided a descriptive profile of individual children.

Parents tended not to answer questions which were confusing and meaningless, and different response rates between parents of case (52%) and control children (19%) suggested that face validity was better for children with disability. Overall, very few items were missed in any one questionnaire, and parental comments suggested that the questions made sense to parents.

There was a high level of concordance between domain scores achieved by the LAQ-G and a separately administered functional limitation code, suggesting that parental perceptions of their child’s participation was broadly consistent with medically-derived assessments of functional ability. In addition, domain scores showed some predictable variations between diagnostic groups, although the numbers involved were very small, and no calculations of statistical significance could usefully be undertaken.

Strengths and weaknesses of the study

The sample was selected by identifying children on the Northumberland special needs register in the month of their birthday and de-selecting some of the children with simple developmental and/or language delay to ensure a reasonably balanced quota of disabilities. This was clearly subjective, and will have introduced a degree of selection bias in favour of children with less common disabling conditions.

Parental response rates were 52% for case and 19% for control children, and this appears quite low, although there is no consensus about what could be considered “acceptable” response rates. Certain incentives, such as follow-up mailings or other techniques will improve returns [1] but our Ethics Committee stipulated that parents should not be approached again if they did not elect to complete and return the questionnaire first time around. Parents of disabled children were more likely to have found the content of the questionnaire relevant to them and their child, and this would explain why their response rate was better than for parents of control children.

There was no statistical difference in terms of presence or absence of an educational statement between respondents and non-respondents for case children, but it appeared that parents were more likely to respond if their child had a significant or severe disability. It is therefore possible that there was also a degree of respondent bias, and that children from the more severe end of the disability spectrum were over-represented in the development of the LAQ. This is of course the group of children whose experience a special needs register is most interested in capturing. However, one of the desired attributes of the LAQ-G was that it should discriminate between children with different levels of disability. This research looked at differences between case and control children, and with case children representing possibly the more severe end of the disability spectrum, it is perhaps not surprising that a statistically significant difference was evident. Larger groups of more diversely affected children will need to be looked at to see at which point the scores achieved by a child with a very mild disability become indiscernible from those achieved by controls.

Reliability of the LAQ-G at item level appeared fairly robust, except for the question probing longer outings, where controls actually scored higher than cases, although the difference was not statistically significant. The same question was also contained in the cerebral palsy LAQ, where it was a good discriminator between various levels of disability, so the question has been retained and the results it generates in future studies will be monitored.

Although not statistically significant, there were more differences between questionnaire completions for case than for control children. One explanation could be that for control children, the majority of item scores were 0 (i.e. no

problem), and this was unlikely to vary between completions, whereas case children were likely to show subtle day to day differences, which would be reflected in their repeat item scores.

Although there is no clearly established guidance about the number needed to derive a useful domain structure by whatever means, the numbers of case children, and subsequently the data matrix used for developing domains through MDS, are relatively small, and the descriptive profile could change as a result of increasing the sample size. The use of MDS itself in deriving a domain-based structure is unique [2]. Its major advantage lay in the fact that it was a technique specifically developed for use with ordinal data, and that the grouping or structuring of items depended entirely on how parents answered the questions. It was therefore a very “clean” illustration of parental response. The disadvantage lay in the eventual decision about where to include items and how to name domains, as this was necessarily a subjective process. The Cronbach alpha analysis was undertaken to check for internal consistency, ensuring that items were allocated to appropriate domains. Our alpha scores ranged from 0.66 to 0.91. Alpha should be above 0.70 (although some accept values as low as 0.50 [3]) but no higher than 0.90. The lower alpha values in the *domestic life* and *interpersonal interaction* domains suggested that the scale was in fact tapping more than one trait, and the higher alpha value in the *self care* domain may have been due to the unnecessary inclusion of items within that scale [1]. Finally, there are unequal numbers of items in each of the health domains identified by the application of MDS, and this introduces a subtle form of weighting.

There was no other tool designed to capture impact of childhood disability which could be used as a “gold standard” with which to compare results, and this was a considerable challenge in terms of validation. Comparing domain with functional limitation scores, and looking for predictable differences between diagnostic groupings, are acceptable methods of construct validation, but the low overall numbers do not allow meaningful comparisons to be made and larger numbers of children would allow a more precise picture to emerge about how the LAQ-G performs in different diagnostic groups.

Characteristics of the LAQ-G

The specific objectives of this research were to develop a tool with a number of attributes:

It needed to be appropriate for use with special needs registers, and as such should *discriminate* between children with different levels of disability. Certainly the above results confirm that the LAQ-G discriminates between children with or without disability. The LAQ-G looked at the current health status of children at a given point in time and as such provides a reliable “snap shot”. The questions contained within the LAQ-G explore the consequences of children’s disability on life and family, and therefore the LAQ-G captures *participation* rather than disability itself. The questionnaire was completed, and meaningful results obtained from parents of children with a range of disabilities, confirming its use as a *generic* tool. Finally, by using a multi-dimensional statistical technique, it was possible to structure answers to

questionnaire items into a model which could be mapped on to *health domains* analogous to those contained within the International Classification, thus providing meaningful descriptive profiles of children's experiences.

While developing the LAQ-G, we were continuously asking ourselves which factors we should attempt to capture, what information was useful and relevant and most importantly, who should be the ultimate judge of what matters most?

Activities of daily living (eating, dressing, going to the toilet) are essential to stay alive, and if children cannot do this for themselves, other people will do it for them. Other activities are more discretionary, such as participating in after-school activities: football club or music lessons, which may follow a "normal" distribution within the population, and looking at participation in these activities would also be useful. The LAQ-G included questions which captured information from both these aspects of a child's experience.

Development is a key feature of childhood, and not only is it important to understand a child's disability in the context of their developmental level, but it was also important to look at how disability in one health domain (mobility) impacted on development in other domains (psychosocial or emotional). Therefore an appropriate measurement tool did need to include some expert testimony on what is necessary for optimal development, and there was considerable professional input to creating the LAQ-G.

Equally important were the views of parents and children, who needed to have an opportunity to say what was important to them. Development of the LAQ-G was started almost ten years ago. If this process were to be repeated today, the views of Northumberland parents and children would be sought directly (for example with the use of focus groups) rather than relying entirely on the findings of separate surveys. The LAQ-G was completed by proxy (parent or main carer) rather than by children themselves, and it is well established that there can be important differences between parent and child perceptions of the consequences of disability or chronic health problems [4-6]. However, given the young age and possible intellectual impairment of the children involved, it was felt that reports of parents were acceptable for the purposes of enhancing the information on a special needs register with objective health status data.

Reliability of the LAQ-G is very good at item level. Assessing its validity has been more of a challenge, as described above, but results so far have been encouraging.

In terms of technical properties, the LAQ-G was only validated as a descriptive/discriminative tool, and as such could only be used to discern differences between individual or groups of children at a given point in time. We cannot say at present whether the LAQ-G would be capable of detecting changes in children's item or domain scores in response to therapeutic and/or service interventions, and it has not yet been demonstrated that the LAQ-G has the sensitivity to pick up changes over time if such change actually occurs

(i.e. whether it has the necessary properties of an evaluative tool). Similarly, further longitudinal studies will be necessary to assess whether a particular score in a child predicts that child's clinical course (i.e. whether the LAQ-G has the properties of a predictive tool).

In terms of application issues, in its current format, the LAQ-G takes fifteen to twenty minutes to complete, and this may still be too lengthy for busy parents with significant care responsibilities.

The health domains generated by the LAQ-G could be mapped on to six of the ICF's nine domains of participation, but two important issues need to be borne in mind:

- the initial process of item generation did not seek to capture the specific details of the ICF categories, and therefore not all ICF domains are represented
- although the ICF has given coverage to characteristics of disability which are particularly relevant to children, such as learning, behaviour and some experiences concerning school and family, it was written primarily for adults.

The environmental context of all children's experience is first and foremost their family [7], and the LAQ-G acknowledged this important fact by seeking information from the child's parent or main carer, and by including questions pertaining to family and sibling relationships.

Future plans

The next phase of this project will involve routine completion of the LAQ-G by Northumberland parents of children undergoing assessment of special educational need for whatever reason, possibly using an extended age range to cover the whole period in first school (5 to 9 years). There are also plans to use the LAQ-G in two separate surveys in North of England: one seeking to establish a Regional Register of children with autistic spectrum disorder, and a second study, in collaboration with the Family Fund in York, looking at the associations between activity and participation, and how both affect decisions made by the Family Fund. This should provide a considerable amount of additional data for more detailed validation, for example testing other hypotheses (such as comparing the descriptive profiles of children in receipt of respite services with those who aren't), or looking at differences across ages, by severity and by diagnosis.

It will also be desirable to reconsider application issues such as mode of administration and length of the questionnaire. Certain items (for example, the one item which scores higher in controls than in cases, or those which are regularly missed) will need to be reconsidered, and it will be important to see how the LAQ-G generally performs in larger groups of correspondents. The fact that domains have different numbers of items, and the subtle weighting of items occurs as a result, will also need to be addressed in the future, possibly by using a ranking procedure to identify superfluous items within domains.

Meanwhile, the LAQ-G already provides a useful “snapshot” of a child’s and family’s experience, from the parental perspective, in a format which allows easy incorporation into a district special needs register. Its use will enhance the information on such registers, which could be used to highlight areas of disadvantage and evaluate current care provision for children experiencing different types of disability or living in different localities, as well as improving epidemiological information generally and allowing clinicians and service planners to assess children’s health care needs with greater precision in the future

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