Changes in quality of life as a result of ketogenic diet therapy: A new approach to assessment with the potential for positive therapeutic effects

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1. Introduction

It has long been established that children with epilepsy have an increased risk of developing psychological and neurodevelopmental problems that are persistent and distressing. The Isle of White Study [1] in the 1970’s found that children with epilepsy had high rates of psychological problems. These findings were confirmed in the later studies by Goodman [2]. Children and their families with complicated and difficult-to-treat epilepsy have high levels of anxiety and distress exacerbated by the unpredictability of seizures and the coexistence of other factors such as physical and learning disability or a life limiting neurological condition. Life can seem bleak and quality of life poor as families feel helpless and hopeless about influencing the future. Quality of life, however, has many dimensions, raising the question about how it is measured and, more crucially, how it is defined and by whom.

Quality of Life is an important outcome for children with chronic health conditions and their families. However, the concept has been ambiguously defined, has varied across and within conditions, and there has frequently been a lack of agreement in ratings between families and proxy raters. Many standardized tools and measures have been developed and well validated that try to capture the impact of disease on Quality of Life. These include generic measures such as the PedsQol [3] and the Child Health Questionnaire [4] (CHQ) and measures specific to epilepsy such as the Quality of Life in Childhood Epilepsy Questionnaire (QOLCE) [5]. However, shortcomings are evident in many of these tools when they are applied to populations with disability.

There are difficulties inherent in measuring Quality of life (QoL) in patients with chronic illness, including agreement on definitions of quality of life and the type of measure used, disease specific or generic. Well validated Qol instruments for epilepsy exist but focus on capturing common themes pertinent to children and families as a group instead of focusing on themes important to individual patients and their families/carers. In addition, it is common for numerous items on these inventories to be left incomplete or responded to with “not applicable” since many of the items are not suitable for children with disabilities and their families. This led us to devise a new approach to capture individual quality-of-life measures that are linked to parental/carer expectations in families of children undergoing ketogenic diet therapy for epilepsy. As part of our routine clinical assessment, parents/carers were asked to describe what they would like to see happen or change as a result of their child being on ketogenic diet therapy. A simple unstructured form was designed to facilitate the assessment process. Parents were then asked to rate their own QoL against these criteria on a Likert scale of 0–10 prior to commencement of the diet. This assessment was repeated at subsequent visits with parents/carers initially blinded to their original responses. Our assessments indicated that ketogenic diet therapy improves quality of life over a twelve-month period when measured against parental expectations. This ideographic approach has demonstrated changes in parental Qol and parental perceptions of their child’s quality of life that would not have been captured by other validated measures. A lengthy questionnaire is avoided and is replaced by a skilled supportive conversation that identifies goals for treatment that are important to parents. This helps parents to reflect on the progress their child makes on the diet by revisiting their previously stated aspirations, and assessing whether they have been achieved. This is particularly helpful for those parents who express a sense of failure or helplessness relating to their child’s intractable epilepsy. As a result, future work will center on developing this approach as a clinical tool.

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Examples of questions include:

1. **PedsQoL: how much of a problem has your child had with:** running; lifting heavy things; helping to pick up toys; doing chores around the house?
2. **CHQ: how satisfied do you think your child has felt about his or her school ability; friendships; life overall; has your child been limited in the amount of time s/he could spend on school work due to emotional difficulties?**
3. **QOLCE: Compared to other children of his/her age how often has your child: had difficulty reasoning or solving problems; had difficulty making plans or decisions; had difficulty keeping track of conversations; completed activities that needed organizing and planning?**

While these high-quality tools capture certain themes pertinent to some families, many of these items would be rated “not applicable” to children with intractable epilepsy and coexisting neurodevelopmental difficulties. Many of these questionnaires are lengthy and are not suitable for use in busy routine clinical practice. A further problem is that what the clinician believes constitutes a good quality of life may be far from the reality of the patient. Previously published work in the field of epilepsy surgery found that patients’ aims for surgery did not focus solely on or prioritize seizure reduction as a positive outcome of the surgery, although this may be the physicians’ rationale for surgery [6].

2. Methods

A new multidisciplinary service for Ketogenic Diet Therapy was commissioned in Newcastle-upon-Tyne in 2012 for children with intractable epilepsy. It comprises a pediatric neurologist, pediatric Dietician, clinical pediatric neuropsychologist, and neurology nurse specialist. The issues discussed above led us to consider new ways of working with children and families to try and capture what is important to them, guided by 7 key aims:

1. To gather information about the actual issues that cause distress and are important to families and impact on their quality of life.
2. For this to be part of routine clinical assessment and follow up and not be burdensome.
3. To make individual aims explicit.
4. Not to reinforce the many things that the children are unable to do and compound existing levels of helplessness and psychological distress.
5. To focus on what may be achievable.
6. To be accessible to parents/carers of all levels of ability.
7. To hold in mind the World Health Organization’s definition of quality of life: “the child’s perception of their position in life...in relation to their goals, expectations, standards, and concerns”.

The work published by Taylor et al. [6] on establishing patient expectations formed the foundation of our approach since it makes sense intuitively that if people are not standardized then neither is their quality of life (Table 1).

As part of our clinical assessment of children and their carers, a single unstructured form was devised to assess quality of life that filled no more than a single sheet of A4 paper and that captured the 7 aims described above (Fig. 1). All of the children on the ketogenic diet had moderate to severe developmental delay, so the parents completed the form. The intention was to capture changes in quality of life for the family as a whole that might result from improvements in the identified hopes and expectations. The form includes a brief rationale explaining what the form is for, followed by a small box for parents to enter their expectations of the ketogenic diet. The box is small so that it does not overwhelm parents, particularly those who are not confident in expressing their views or who are not confident writers. Underneath the box is a simple scale from 0 to 10 (10 being as good as can be). Parents are asked to complete the form and to rate their quality of life against these expectations based upon how things are before they start the diet.

The form was mailed to parents along with some other information about the team, and a food diary prior to the first appointment in the pre-assessment clinic. Parents therefore completed the form before they had any contact with our team so that their views were not influenced in any way. This was returned by mail prior to the family being invited to attend a pre-assessment clinic that is jointly facilitated by the neuropsychologist, dietitian, and neurology nurse specialist. During this clinic visit, the stated parental expectations were discussed, which allowed the team to understand what is important to the family and at the same time address any misunderstandings about what may be achievable for their child on the diet. Additional questions asked as part of the skilled psychologist-led discussion included “What would be different?” “How would it be better?” “How would they know?” The presence of a skilled psychologist as part of this discussion was paramount since such discussions can be highly emotional for parents/carers and the existence of significant mental health issues may be revealed. Further, one to one sessions with the psychologist can then be offered to address these issues or to appropriately refer or direct parents to local services. The families attended follow-up clinics at 3, 6, and 12 months where they were seen separately by the neuropsychologist and re-rate their QoL based on their original hopes and expectations but blinded to their original ratings. Diet duration was a minimum of 3 months and maximum of 24 months in conjunction with international recommendations. Data included in this paper covers a time period of twelve months on the diet, but some of these children remained on the diet for two years. Data were collected between January 2013 and July 2015. No children/families discontinued the diet, and we attribute this to a rigorous pre-assessment process that identifies families/children for whom the diet may not be manageable or appropriate.

Of the 12 children included in this paper, 9 children were prescribed the classical ketogenic diet and two a modified diet. All the children had diagnoses of severe intractable epilepsy including: Lennox Gastaut syndrome, migrating partial seizures of infancy, Aicardi syndrome, Dravet syndrome, lissencephaly Angelman syndrome, myoclonic absence and generalized tonic clonic seizures, and epilepsy without specific classification. The age range of the children on the diet was 3 months to 17 years. Median age of the children was 3 years 6 months.

### Table 1

Examples of the criteria and expectations that have defined parental quality of life.

<table>
<thead>
<tr>
<th>Specific expectations that have resulted in the above QoL improvements have included:</th>
</tr>
</thead>
<tbody>
<tr>
<td>To see my child smile</td>
</tr>
<tr>
<td>I’d like my child to recognize me</td>
</tr>
<tr>
<td>I would like to cuddle our child</td>
</tr>
<tr>
<td>To see some developmental progress</td>
</tr>
<tr>
<td>To see a reduction in seizures</td>
</tr>
<tr>
<td>To reduce medication, if we can get rid of one drug...</td>
</tr>
<tr>
<td>Child to be more alert</td>
</tr>
<tr>
<td>To see child hold his head up</td>
</tr>
<tr>
<td>To see my child happy</td>
</tr>
<tr>
<td>To get my child out of nappies so that we can go out as a family</td>
</tr>
<tr>
<td>My child can hold my hand now</td>
</tr>
<tr>
<td>I’d like my child to react when bloods are taken</td>
</tr>
</tbody>
</table>

3. Results

A total of 25 children were initially seen in the pre-assessment clinic between January 2013 to time of writing by the Newcastle Ketogenic Therapy Service. Of the 25 children seen, 5 did not start the diet either because the families decided that they were unable to commit the time required, or because personal circumstances would have introduced an additional stress for the families. One child died due to deterioration in medical condition, and five were weaned from the diet due to changes in medical presentation which meant that the diet was no longer considered appropriate. Data for a further three families were not provided as only the baseline measurement was available at time of writing. Data are presented in Fig. 2 for 12 parents whose children had started the diet; this includes those who remained on the diet for at least a year. Our routine clinical assessment showed that for the
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