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1 Introduction

Trends in modern healthcare have led towards "shared" or "partnership" models of service provision, which in turn have been accompanied by an emphasis on higher quality standards of care and increased accountability to service consumers (Lasalvia et al., 2012). Assessing the quality of services from the perspective of the consumer has become increasingly important, and patient satisfaction has become the variable that is most often used as a metric of service quality (Crow et al., 2002). Assessing consumer satisfaction can assist in improving existing services as well as identifying needs for additional services. Perhaps equally importantly, consumer satisfaction has also been linked to outcome variables such as patient attitudes and health-related behaviours such as treatment adherence (Joosten et al., 2008).

Consumer satisfaction is therefore not only of interest to prospective healthcare users, but also clinicians, healthcare managers, public policy analysts, politicians and commissioners of services. However, despite its importance, there have been considerable problems in both establishing a tangible definition of satisfaction and in its accurate assessment as a healthcare variable (Crow et al., 2002). As a result, the assessment of patient satisfaction has been described as "an elusive discipline fraught with misconceptions and conclusions based upon the most tenuous of evidence" (Hansen et al., 2010, p.485). Such difficulties may in part reflect the diversity of healthcare services over which satisfaction is examined. As a result a range of methodologies have been employed, the most common of which include questionnaires and examining users' experiences directly through interview (Crow et al., 2002). Correspondingly, in child healthcare settings, parents or carers are most commonly interviewed or asked to complete measures to ascertain their level of satisfaction (e.g. Krahn et al., 1990).

Whilst multiple studies have been conducted in services for children with autism spectrum disorders (Bitterman et al., 2008), child and adolescent mental health services (Lambert et al., 1998), speech and language services (Campbell, 2000) as well as those in medical services (Halfon et al., 2004), to date only two studies have examined patient satisfaction within the context of paediatric neuropsychology.

Paediatric neuropsychology is a specialist discipline that examines the dynamic and on-going interaction between the brain, development and environmental context (Holmes-Bernstein, 2000) as well as a range of differing socio-cultural issues that impact on both the child, the family and educational systems (Baron, 2004). As such, paediatric neuropsychology represents the integration of knowledge of the brain, on-going development and the influence of the environmental context and examines these in relation to the child's cognitive, behavioural, emotional, social and adaptive functioning (Warner-Rogers and Reed, 2008). Within the UK clinical paediatric neuropsychologists typically provide specialist diagnostic assessments and / or treatments to children who present with "cognitive, behavioural or educational changes in the context of actual or suspected neurological illness or injury" (Division of Neuropsychology, 2004). In recent years there has been an increasing amount of academic literature relevant to paediatric neuropsychology. However, whilst such studies are necessary for clinical practice, they tend to be academic in their focus. Correspondingly, there is perhaps a surprising dearth of studies examining paediatric neuropsychology in applied clinical practice.

Of the two published studies examining patient satisfaction within paediatric neuropsychological services, both were conducted in the USA and employed questionnaire-based measures. The first, by Farmer and Brazeal (1998), involved the design and administration of the Assessment Impact Questionnaire (AIQ) to measure parental perceptions of the effectiveness and satisfaction with paediatric neuropsychological assessment. Parents rated the written report, time spent with the clinician and oral feedback as the most useful components of the assessment, and reported high overall levels of satisfaction. Furthermore, high levels of satisfaction correlated with having their concerns addressed, receiving help to understand their child's strengths and weaknesses and the perceived usefulness of practical suggestions of how to deal with their child's problems.

A second study, by Bodin and colleagues (Bodin et al., 2007) extended Farmer and Brazeal's (1998) work by combining the AIQ with the Client Satisfaction Questionnaire (CSQ-8; Attkisson and Greenfield, 2004), a standardised measure of satisfaction for which normative data is available. The combined measure was then supplemented with items from the Measure of Processes of Care (King et al., 1995)

and eight novel items designed to measure aspects more relevant to their local service provision. Again, a high level of satisfaction was reported (82% rated mostly or very satisfied), and factor analysis suggested four underlying factors which were labelled: (i) overall satisfaction, (ii) clinician acceptance / empathy, (iii) provision of help, and (iv) administrative / facilities.

Whilst both of these studies have provided useful information, both have relied on questionnaires with unclear methods of development. Furthermore, parents' perceptions and experiences of paediatric neuropsychology are likely to be unique and subjective, and these experiences are unlikely to be wholly captured within a questionnaire format. It is equally important to note that both studies were conducted in North America, where the provision of healthcare follows a radically different model to that delivered within the UK, limiting generalisability of these results to UK paediatric neuropsychological practice. Such questions are important for UK based clinicians if they are to rely on parents and teachers to make changes in the systems around the child to implement change. The current study aimed to address these shortcomings through using Bodin et al.'s (2007) questionnaire, and supplementing this with interviews of parent's experiences based upon UK clinical practice.

2 Method

2.1 Setting

The evaluation was conducted in a specialist paediatric neuropsychology service in the UK. It forms part of a specialist regional neurosciences centre and its primary remit is the provision of neuropsychological assessments for children and families under the care of the hospital's neurosurgeons and neurologists.

2.2 Materials

Materials consisted of a postal survey, previously used by Bodin et al. (2007). Questions regarding insurance provision were not suitable for an NHS context and were removed. The survey was supplemented with questions regarding the child's age, gender, reasons for referral to the service and an invitation to attend an interview. For this, a semi-structured interview was developed, informed by paediatric neuropsychology texts (e.g. Davis, 2011) and via consultation, planning, and refinement with clinical neuropsychologists. The interview aimed to cover all aspects of outpatient service provision, including parental expectations, the assessment process, the feedback session and products of service provision such as the written report.

2.3 Procedure

All children (n=51) who had attended an outpatient assessment within the prior 12 months were identified. Of these 51 children, medical records indicated that seven were undergoing complex medical treatment, and three were deceased; the parents of these children were not contacted. The remaining 41 families were sent a postal survey and an invitation for interview, and a follow-up copy two weeks later to maximise the response rate. Interviews were audio-recorded and transcribed verbatim by the lead author.

3 Results

3.1 Demographic Information

A total of 18 responses were received (43% response rate), higher than other studies of parental satisfaction (e.g. 35%; Bodin et al., 2007). The respondents rated neuropsychological assessments of children who ranged from 4 to 17 years of age (Median = 11.5, Inter Quartile Range [IQR] = 9.8 - 14.3 years). Half the children were male. Reported primary diagnoses included hydrocephalus (27.8%), brain tumours (27.8%), epilepsy (11.1%), demyelinating disorders (11.1%), genetic disorders (11.1%), traumatic brain injury (5.6%) or were unknown (5.6%). Specific details have not been provided to ensure anonymity.

3.2 Survey Data

Extraction and summation of the CSQ-8 items from the survey demonstrated that overall level of satisfaction (mean = 27.59, standard deviation = 3.43) was not significantly different from mean scores for a range of other healthcare services (e.g. mean=27.8, standard deviation=3.57; Attkisson and Greenfield, 2004). Examination of individual items demonstrated generally positive ratings of parental satisfaction. All respondents indicated that they were either mostly or very satisfied with the service received, with 82% rating the quality of the service as excellent. The most negative ratings were associated with items related to the identification and signposting to other professionals or groups who could provide further help, with 40% stating they were not sure or disagreed that this was provided.

3.3 Interview Data

Of the eight interviews conducted (median length = 66 minutes), seven were with mothers. Comparison of survey responses indicated that those interviewed were significantly more likely to state a higher level of satisfaction on the survey (U=13.0, p=0.02, r = -0.56).

A critical realist perspective to thematic analysis was used to analyse parents' transcripts based upon the procedure laid out by Braun and Clarke (2006). The procedure is comprised of six phases; the first stage involves familiarisation with the data through transcription of the audio recordings and repeated readings of the text. Initial codes were generated and aided in grouping data and identifying relevant patterns across parents' experiences. Proto-themes were then identified, which underwent a cyclical process of review, refinement, combination and deletion. The data were continuously referred to, ensuring that abstract themes were represented in the data corpus. The final themes were then identified and named.

The analysis identified four major themes which were labelled: (i) what the parent brings through the door; (ii) service delivery; (iii) role of the service in family's lives; and (iv) overall value of the service.

3.4 Theme I: What the parent brings through the door

3.4.1 Practical Aspects of Healthcare

This theme was by far the most salient within the parents' narratives and related to their journey through the healthcare system with their child. These typically focused upon the practical aspects of their health care, and whilst the predominant focus was on the child and the parent present, each parent discussed the impact on the family as a whole. These were characterised by their factual nature, detailing the child's condition and journey.

"she was referred on the Thursday, that was when we got the results, and were told there was a bed waiting for her, and we just drove straight there." Parent 7.

3.4.2 Current Level of Functioning

All parents contributed data to the second subtheme, which concerned their child's current level of functioning, including the impact of their child's condition, and how this affected them both at home and at school. Findings of a range of cognitive, behavioural and emotional sequelae are almost universally recognised after braininjury, the severity of which vary depending on numerous factors (Davis, 2011). Whilst all parents spoke of this, five parents went on to discuss the contrast between their child's abilities, and the first impression they made to others. Parents felt that their child's difficulties, whilst substantial, were concealed to most people on initial presentation. This was a key factor for these five parents who all discussed the disparity between their child's superficial presentation and the deficits that are concealed to most people.

"When somebody asks him how he is, he says 'on the contrary how are you,' you would think 'my goodness, what's this family talking about?' And the reality is when he's at home he's himself, so he can scream at decibels only dogs can hear... and he does do that." Parent 4.

Findings of "hidden" difficulties after paediatric brain injury are common, and have long been identified (e.g. Harris et al., 1989), and for these five parents this in itself was a direct cause of further difficulties.

3.4.3 Emotional Impact on Parents

The final subtheme consisted of detailing the way in which their child's condition had impacted upon them emotionally. In this instance there was a significant amount of variation within the parents' narratives, which reflected the nature of their child's condition. For example, there was an implicit theme of shock and trauma for those parents whose children had suffered an acute injury or had received an unexpected diagnosis.

"I remember walking down the corridor at [the hospital] and wondering if I'd died because my life was just so... strange." Parent 5

In contrast parents of children with congenital injuries or difficulties, spoke of the longer-term, more chronic nature of the difficulties they experienced. Whilst some parents, such as parent 2 below spoke of suffering from depression, there was an implicit thread of continued grieving for many parents. Parent 3 explicitly discussed an on-going grieving process, which was re-instigated at times when the disparity between their child's chronological age and their developmental abilities was highlighted. Examples included her child reaching an age when their peers were travelling independently to school, but the child in question was not able to do this due to a lack of road safety awareness.

"I've recently seen a doctor and am taking anti-depressants. Not because I'm a depressive person but because I got to a point I didn't feel I was coping with life very well, and part of that is having a child who takes so much out of you." Parent 2.

"And I always call it part of the grieving process, you've got a child, and every now and again you go through a spell where you think they're never going to do that, and you do grieve, and you do still do that, and it does still get you down on regular occasions. I still do that." Parent 3.

3.5 Theme II: Service Delivery

Parents were asked directly about their experience of attending a paediatric neuropsychological assessment, and three subthemes emerged from the data.

3.5.1 Negative affect in attendance

The first subtheme was focussed around negative affect which predominantly occurred prior to attendance. In all cases parents reported anxiety characterised by the lack of certainty over the specific aims and purpose of the assessment, or the practicalities involved for both their child or themselves.

"It's just nerves isn't it? I suppose it's the unknown. It's the brain thing I guess isn't it - are they going to find anything, are they not going to find anything?" Parent 6.

3.5.2 Therapeutic Engagement with the Family

Therapeutic engagement was discussed by seven parents, and formed the second major subtheme. Of those parents who commented on this, all emphasised the importance of the clinician's interpersonal skills. Not only was this reported to ease anxiety, but also aided in creating a safe, comfortable environment which allowed parents to talk openly, ask questions, feel understood and to be able to discuss the realities of their child's difficulties in-depth.

"[the clinician] explained everything so well, you just sort of felt comfortable with it...she made us feel at ease straight away, and you could tell she had interaction with [child] straight away." Parent 6.

3.5.3 Parental Value of Reports

Following the face to face assessment, a report is written detailing the assessment process, findings and opinion regarding the child's strengths, weaknesses and specific difficulties. In addition to these findings, reports typically have conclusions and recommendations that can be implemented by both parents and teachers to improve the child's wellbeing ability to learn and function on a day to day basis.

 Parents were asked for their opinions of the report and their experiences of implementing it. Whilst all parents agreed that the report had ultimately been useful, there was a discrepancy in the manner in which parents reported using this document, suggesting it served different roles for different parents. For instance, parent 5 reported their perception that the report was written for other people:

"I only read it once, and put it down and went onto the next thing." Parent 5.

Alternatively parent 3 reported repeatedly reading the report, finding it a source of re-assurance:

"I also feel that when he's got a problem, and I see that in black and white it helps me think that I'm not overreacting, and there is a massive gap there, or a massive gap here, or he has got strengths here. It just makes me feel better - its reinforcing what I already know... but it makes me feel better about it." Parent 3.

The parental narratives indicate that the reports were used for different purposes, and as a result different levels of emphasis or importance were placed upon them. However, all parents agreed that they found there had been negative aspects of the report. Again, this was characterised by a discrepancy in parental views of the specific aspects of the report. For example, whilst some parents felt the reports were too lengthy and were overly complex, others appreciated the thoroughness and the depth of analysis contained within. In addition to this, there was a fear that the complex nature of the report may deter others (in particular educational staff) from reading the report and implementing practical recommendations.

"I'm interested in all this stuff, and I like reading it, now obviously I'm an advocate for [the child], but my eyes were glazing. Do I need to know this? I don't know. I just need to know how it impacts on [child]... the most constructive bit is the recommendations, at the back." Parent 1

"I'd underlined the bits I thought were relevant for school, but I passed it to school and remember thinking they'll never read that, they'll just see 7-8 pages and think 'bloody hell." Parent 4

3.6 Theme III: The role of paediatric neuropsychology

All parents discussed the role and impact the assessment had had, both for their child, and also for themselves. Four main subthemes were identified.

3.6.1 Insight into the Child

The first of these subthemes was labelled "insight into their child," and was described by all parents. Parents reported that not only had the assessment process confirmed what they already knew about their child, but they had also learnt new information pertaining to their child and their abilities. Whilst in all cases such insight was concerned with the negative after-effects of their child's condition, some parents also described newly identified strengths, which they were previously unaware of.

"I just found it gave me a really good insight, especially when we were doing the names, the pictures of people because he was really good at that, and it kind of highlighted his strengths and weaknesses for me, and more, more than what I'd been aware of. It kind of brought them out more." Parent 3

3.6.2 The Importance of Practical Strategies

Whilst parents had previously discussed how they valued the practical advice given at the end of the report, seven parents emphasised the importance of practical utility of the report and recommendations. This appeared to relate to their own engagement with their child, in addition to how others approached their child in particular educational staff.

"What I wanted at both sessions, and in the report to a certain extent were the strategies for learning, or the strategies to support the people who are teaching him." Parent 1.

3.6.3 Supporting Others to Understand the Child

The third identified theme related to supporting other people to understand their child. Seven parents spoke of the importance of this role, and in each instance it related to the educational system. Whilst practical strategies discussed above were important, parents also relayed the importance of teachers' understanding how each condition affected the respective child. Parents felt that understanding occurred through both the report, and in particular the recommendations, and also through clinicians' direct engagement with the school system.

"...so [clinician] said she'd go in and do a talk to them. So I think that it's just such a huge bonus that we didn't realise was available to us, and as far as we're concerned it's just made the world of difference in [child's] world." Parent 8

3.6.4 Advocating for Families

The final subtheme related to advocating for families, and was viewed as another key role for the paediatric neuropsychologists. Six parents described having experienced difficulties when engaging with external systems and agencies. Whilst there was a discrepancy between parents in whether the service had engaged directly with the school system, all parents agreed on the valuable nature of this as a potential option. The value appeared to be motivated by two factors, firstly that teachers were more likely to make changes as a result of direct clinical outreach, and secondly that the parent's relationship with the school could be protected - parents felt they no longer had to be characterised as "a difficult parent." Not only did they feel that someone else was able to convey the same message they had been attempting to convey, but that this was more powerful when articulated by a clinician, with change more likely to occur as a result.

"...they don't always listen to what you're saying. So for it to come from someone else, it kind of takes the pressure off and stops me from being the bad guy... It's kind of an escape route for me." Parent 4

3.7 Theme IV: Overall value of paediatric neuropsychology

The final theme consisted of parents' views and opinions of their overall experience of paediatric neuropsychological assessment. Perhaps surprisingly, the narratives did not focus on the factors directly related to the service, but appeared to summate the value and meaning their assessment held for them. In all instances, parents recorded a positive experience, emphasising not only the unique nature of paediatric neuropsychological assessment, but also the beneficial impact it had had on their child's life.

"As far as we're concerned we feel very blessed that we've had the service we've had" Parent 2.

"There's nothing else out there that gives you this information about your child" Parent 3.

"[the assessment] was just brilliant, we couldn't have asked for anything else" Parent 6.

4 Discussion

4.1 The Assessment of Satisfaction

The current study used a mixed-methodology approach to examine experiences and levels of parental satisfaction after attending a paediatric neuropsychological assessment with their child. Satisfaction is a variable commonly used as an indicator for the quality of services (Crow et al., 2002), and previous studies in the area have reported high levels of satisfaction on the basis of quantitative measures (e.g. Bodin et al., 2007). The quantitative results from the current study correspondingly found a high level of satisfaction. It is hypothesised that the option of returning questionnaires anonymously likely increased the probability of honest answers and a closer reflection of parental views. Not only was the finding of a high level of satisfaction comparable to previous studies (Bodin et al., 2007, Farmer and Brazeal, 1998), but it was also comparable to the normative data available through the use of the CSQ.

4.2 Beyond Satisfaction: The Importance of Parental Experience

The trend for high ratings of satisfaction from healthcare consumers has previously been commented upon (e.g. Bickman, 2000), questioning the utility of such findings. Whilst negative responses were received within the current study, these did not appear to impact on overall level of reported satisfaction. As such, we would suggest that the questionnaires do not capture the range and complexity of factors and moderating variables involved in parental satisfaction. Parental levels of satisfaction in such a specialist service may well be dependent upon a range of other factors. These may include the family's experience with other healthcare services related to their child's condition, or their expectations of what a paediatric neuropsychological assessment may be able to provide. As a result the questionnaires are likely to constrain parental views of the clinical paediatric neuropsychology service.

4.3 The Value of Paediatric Neuropsychological Assessment

In order to mitigate short-comings with questionnaire measures in this context, it was decided to complement the questionnaire with an interview that allowed parents to voice a wider range of experiences. Thematic analysis was employed as the most appropriate form of analysis, and four major themes were identified. The theme "overall value of paediatric neuropsychology" could be considered to correspond to the high overall levels of satisfaction within the sample. As a result, the degree to which this theme provides additional insight or utility over the questionnaire measure is therefore questionable.

Whilst the overall value of the service was of limited utility, three other themes were identified. The first of these, "what the parent brings through the door," was comprised of by far the most salient narratives. Within this theme parents spoke of the course of events and associated medical treatment that had led to their referral. These same parents then went on to discuss the child's neuropsychological, emotional and behavioural sequelae and how these impacted on their child's functioning at the present time.

4.4 The Role of Paediatric Neuropsychology in the Journey through Healthcare Whilst "what the parent brings through the door" may be considered background material to the assessment process, it has direct relevance in terms of the on-going day to day nature of both the child's and family's life. Interestingly, one of the major factors within this for five of the parents appeared to be the contrast between how their child appeared to the outside world and their true ability level. Findings of these "hidden" deficits have long been recognised in the literature (e.g. Harris et al., 1989), but it was also apparent that this in itself was a major factor in the parent's and family's distress. In itself such hidden deficits are likely to be further related to findings of raised parental stress in children with a range of neurological disorders, increased amounts of perceived stigma, poorer marital relationships and exacerbated social and financial strain (Wade et al., 2001). As a result, it is unsurprising that parents' narratives included increased stress, depression and an on-going grieving process, reflected in the subtheme "emotional impact on parents." Interestingly this varied between parents, and could be considered to reflect the differences brought about by the chronicity of the child's condition. For instance, narratives varied from reactions of shock in cases of acute trauma to more long-term examples of chronic stress, depression and grieving as the child aged but was unable to reach their expected developmental milestones. As such it is evident that parental emotional health is integral not only to the adversity of the events associated with their child, but also to the parent's future expectations of their child, and the level at which they anticipate their child will function. We would suggest that necessary forethought should be given to how the paediatric neuropsychological assessment will highlight the child's deficits and weaknesses, and the impact this will have on the child's support network.

Whilst there may be a difference in the mechanisms of parents' ill-health that are at least part dependent on whether the child has suffered a long-term condition, or whether it is more acute in nature, it is clear there are unmet psychological needs. Whilst traditional mental health services are available, whether parents meet sufficient referral criteria is unknown. Similarly, existing services are only likely to be able to treat individual family members in isolation. The effectiveness of more specialist input that can address difficulties within such families remains an empirical question. However, given the combined prevalence rates of neurological illnesses in

children, it is perhaps surprising that this has not been more systematically investigated.

4.5 The Practicalities of Paediatric Neuropsychology

Two further themes were identified that dealt specifically with paediatric neuropsychological assessments. It was apparent that the parental experiences of paediatric neuropsychology started with the referral, and appeared to be associated with substantial amounts of pre-assessment anxiety. This was related to uncertainty over what to expect from the assessment. However, parental anxiety was quickly alleviated in each case, and appeared to be the combined result of being put at ease by their clinician, and being provided with information. As a result, this highlighted two main points. Firstly, it emphasises the importance of therapeutic skills in the discipline of paediatric neuropsychology. Secondly, it may be that any apprehension or uncertainty can be pre-empted through information provision prior to the assessment.

A further theme, "the role of paediatric neuropsychology" detailed the purpose of the assessment from the parents' points of view. A number of common factors were identified, such as providing an opportunity for parents to learn about their children's specific strengths and weaknesses. It appeared that the primary function of this was so that they could change the way they interacted with their child that improved their level of learning and understanding, and ultimately, how the child functioned day to day. The analysis also revealed that parents particularly valued the role clinicians assumed when supporting teachers and other professionals to understand their child. Engaging with education systems appeared to serve two functions. Firstly, it allowed others to engage with their child in a way that improved their level of understanding and learning. Parents reported that the clinicians were in a position to facilitate change more effectively than parents alone and also protected the relationship between the parent and the school thus reducing parental burden.

4.6 Conclusions

To our knowledge, the current study represents the first qualitative study on parent's experiences of paediatric neuropsychological assessment. It has revealed that existing measures of satisfaction may not encompass the full range of parental expectations and roles of working in paediatric neuropsychological settings. We would suggest this information can be used in two main ways. Firstly, it has provided a number of areas in which adjustments can be made to clinical practice that would aid in improving parental experiences of the assessment process, and in particular, there is clearly a need for further services for children, parents and wider families. also s. and improve . e future. Secondly, we would also suggest that the study can be used to design instruments to better evaluate and improve the effectiveness of paediatric neuropsychological assessments in the future.

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