

# 'They wouldn't know how it feels . . .': characteristics of quality care from young people's perspectives: a participatory research project

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## Abstract

Literature suggests there is a need to hear from children themselves about the quality of healthcare they receive and, although their views are increasingly sought, little is known about children's definitions of 'high or low quality care'. This article reports on a participatory, qualitative study that set out to explore with children and young people whether they could be involved in monitoring the quality of hospital care. Nine young people played an active role in the research process, collecting data from an additional 129 participants aged between 9 and 14. Five characteristics of quality care were identified: 'technical expertise', 'friendly staff', 'respect', 'choice' and 'explanations'.

**Keywords** children's participation • children's rights • patient participation • quality of care

## Introduction

Patients and professionals do not always agree on what constitutes quality care and definition of the term is therefore difficult. Professionals talk about 'quality' frequently but what young patients understand by the term is often unclear. The concept of quality can be different depending on who uses it and in what context it is used. As Mitchell and Sloper (2001: 237) observe, 'theorists, service providers and service users can interpret and experience quality differently'.

A number of studies conclude that young people can not only experience services differently but can also have different expectations of services, both

before and during episodes of care, compared with those of parents and carers (Mitchell and Sloper, 2001; Buston, 2002). When parents give their own views about the quality of care that their children receive, they do so based on their own personal expectations and previous experience, and these do not necessarily match those of their children. Parents have a different evaluative context than their children, built around their own perceptions of satisfaction. Thus there is a need to know young people's perceptions about what constitutes quality care and to find indicators that are relevant to them and their perspective.

In recent years there has been pressure for service users to be involved in both the development of quality standards and outcome measures and in evaluating and interpreting them (Beresford, 2005). The UK government has made a commitment to improve the lives of children, young people, and their families (CYPU, 2001; DH, 2001; DfES, 2004) and one way of bringing the voices of children and young people routinely into healthcare would be to find a way of feeding their views systematically into quality improvement (Hardman and Joughin, 1998).

The idea that children and young people can have views about quality is refuted by the commonly held assumption that they are not competent to make reliable judgements (Franklin, 1995) and that they 'lack the wisdom that comes with experience' (Mitchell and Sloper, 2001: 239). The tendency is to see children as future adults, referring to who they will become, not who they are now. Qvortrup (1994) gives us an interesting division between adult 'human beings' and child 'human becomings' on their way to adulthood. Cockburn (1998: 107) suggests that 'this constant referring of children to their future potentials and possibilities belittles their present actions', and Roche (1999: 486) argues that we need to have regard to the voices of children in the 'here and now'. This suggests that there is a need to gain direct access to the voices of young people rather than rely on proxy reporting of their views about the quality of their care. Mitchell and Sloper (2003) concluded that speaking to children about what constitutes quality care is important because their views differ from those of their parents. So children's participation in service evaluation is essential if services are to respond to their needs so that high quality care can be achieved (Moules, 2002).

A range of studies has enabled young people to voice their perspectives about healthcare (Kari et al., 1999; Buston, 2002; Carney et al., 2003; Horstman and Bradding, 2002; Boylan, 2004). In particular, Doorbar (1996) found that young people could voice their views 'in abundance' if given appropriate methods for doing so. Curtis et al.'s (2004) participants, some as young as four years of age, were able to comment helpfully on their healthcare experiences. The above studies provide evidence that children and young people can evaluate more abstract aspects of care than just the more concrete elements such as décor and food. This literature points to a huge potential in relation to feedback on the quality of care from children and young people.

This article tells the story of a participatory study in which a group of young people worked with the support of a researcher to explore issues around qual-

ity care in hospital. Ethical approval was gained from two NHS Local Research Ethics Committees and informed consent was gained from children and young people, supported from approval by their parents. The ethos of participatory research underpinned the study. This supports systematic reflective inquiry in which researchers and participants actively engage in collaboration, so that 'those normally studied become full participants as active agents in the research' (Bernard, 2000: 168). The participatory nature of the project meant, inevitably, that the precise direction of the study would not be known until the young people became fully engaged as active researchers.

## The beginning

The story began with a question – could young people be involved in monitoring the quality of care in hospital? The aim was to see what young people had to say about their care, whether they thought the care they had received was good enough and whether they could see a way of having their voices heard in the quality monitoring processes. I recruited nine young people (aged 12 to 16 years old, four boys and five girls), who had experienced in-patient hospital care, from a local secondary school (see Moules, 2006, for more details). I started by interviewing them about their experiences. They began by identifying the various clinical and nursing interventions they had experienced. Then they were asked to rate the quality of care in relation to each intervention and to give their reasons.

We analysed the data together using a staged approach adapted from Lacey and Duff (2001). The young people were given anonymised sections of the transcribed interviews and asked to look for reasons given for the various ratings of care. They used A3 paper, coloured pens, cut and paste, and post-it notes to build up their analyses, and their finished work was fed back at the end of a group meeting. Though each of the young people had their own reasons for rating care as they did, there were similarities between the reasons for their decisions and the preliminary coding I had done. It was possible to identify five characteristics which, when present, were more likely to result in care being rated as excellent. When any one of them was absent or partially missing, care was more likely to be rated as OK or not good enough. These five characteristics were *technical expertise, explanations, choice, friendly staff, and respect*.

## A new direction

The young people and I (referred to from now on as the Research Team) subsequently met to discuss how they would like to take the project forward. It was at this point that the young people became more actively involved in the project. It was also at this point that the direction of travel took a rather more risky turn.

Their deliberations led them into proposing talking to nurses about their views on whether children and young people should be involved in monitoring quality. However, ethical and time constraints meant this was not possible. So, instead, they decided they would like to see if other young people might have similar views. The question to be answered was now: Do other children and young people identify similar aspects of good and bad quality care to those identified by the Research Team?

Following a training session about possible data collection tools, and a discussion about the Team's experience, it was decided to collect data using a vignette with the 13–14-year-olds (Year 9) in a local college. Vignettes have been used successfully in a number of projects with children and young people (Fuller et al., 2000; Harden et al., 2000). The five characteristics – *technical expertise, explanations, choice, friendly staff, and respect* – were used as the basis for constructing the vignette. Examples of care (both positive and negative) were used from the young people's own experiences. The vignette constructed became a story about the experience of a young person in hospital after an operation. This form of vignette corresponds to that suggested by Finch (1987: 107), who argues that they are 'short stories about hypothetical characters in specific circumstances to whose situation the respondent is invited to respond'. Thus the vignette sought to understand how children and young people construct their ideas of good quality versus poor quality care. The vignette was converted into a PowerPoint storyboard for use with a group of 9–11-year-olds (Year 5/6) in a local primary school. A show of eight PowerPoint slides containing clip art pictures was shown to the children as members of the Research Team told the 'story'. Each child was given a printed record of the presentation so they could make notes to help them remember the story.

Pupils were given information sheets to take home and those who were interested were able to opt into rather than out of the study. This resulted in the participation of 129 individuals: 84 aged 9–11; and 45 aged 13–14, with 78 boys and 51 girls.

In times set aside for those participating, pupils were asked to listen to the story or read the vignette and then:

- i) pick out the three best and three worst aspects of care giving their reasons;
- ii) rank, in order of importance to them should they be admitted to hospital, the five quality characteristics: 1 being the most important, 5 being the least important (this was given out *after* the other questions had been answered to avoid influencing the answers).

## Analysing the data

The Research Team analysed responses using an adaptation of Framework Analysis (Ritchie and Spencer, 1994). This method of analysis starts deductively from a priori issues, though it reflects the original accounts and observations of the people studied and is thus grounded and inductive (Pope et al., 2000). The a priori issues (the five quality characteristics) were used as the starting point for analysis. This approach allowed all members of the Research Team access to the process of analysis in a practical way, enabling them to share in the process of interpretation. In addition to a thematic analysis of the data, the young people carried out content analysis and an analysis of the data given in the ranking exercise. Analysis took place during three, two-hour meetings.

## Findings and discussion

It was not possible to make any generalizable statements from the data but the Research Team did pick out some major themes from the analysis. The findings in relation to each of the characteristics, *technical expertise*, *explanations*, *choice*, *friendly staff* and *respect*, are now discussed.

### *Technical expertise*

Carney et al. (2003) found that less than half of their sample mentioned 'procedures' during data collection. They expressed surprise at this finding as they had expected children to discuss procedures 'due to their hospitalisation being centred around their medical treatment' (Carney et al., 2003: 34) and they concluded that this was not the most important aspect of the children's experiences in hospital. In this study it was noted that more than half of the respondents (85) identified examples of poor technical expertise as being on their list of 'worst aspects'. Not as many, however, put examples of good technical expertise in the list of 'best aspects'. The Research Team concluded from this that, perhaps, when technical expertise is satisfactory it is less noteworthy than when it is unsatisfactory. More than half also ranked technical expertise as the most important characteristic:

That's the sort of life or death thing isn't it? Without technical skills you could actually die ... wouldn't really care about the rest. (Boy, aged 10)

... because you're in there for operations and stuff you'd want to have the best technical skills possible. (Boy, aged 12)

This finding is supported by the children in a study by Doorbar (1995: 48) where 'carrying out treatments and procedures with skill' was one of six qualities considered important for nurses to have.

Close inspection of the data enabled the Research Team to expand on what might constitute technical expertise. Skill was seen as being important, as many of the respondents commented on instances where staff were '*not able to*' carry out clinical interventions and where interventions that were carried '*hurt*' them. Respondents made references to '*poor skills*' and '*techniques*' and to staff not being trained well enough to be able to deliver care.

The basic element of technical skill tends to be taken for granted in the area of patient evaluation of healthcare. Much is made of interpersonal care and communication skills but less is asked about the quality of technical care. This study shows that young people are not afraid to go against the trend to identify technical competence as the most important factor to get right.

### ***Explanations***

A clear gender difference emerged here with nearly half the Year 5/6 girls and over a quarter of the Year 9 girls noting 'occasions when explanations were missing' as being among the worst aspects of care. In contrast only a quarter of the boys picked these occasions as being among either the best or worst aspects of care in the story. Perhaps this may be indicative of a difference in the ways that boys and girls assimilate and handle information. Further research in this area might be valuable. Children and young people can only participate in their health care if they have sufficient information about what is happening to them. The findings in this study are supported by those from a number of other studies (Buston, 2002; Carney et al., 2003; Mitchell and Sloper, 2003). In addition, the children and young people in this study have shown a desire to be spoken to directly rather than through their parents, a desire supported by the children in the studies by Curtis et al. (2004) and Doorbar (1995). One young person, who rated his care as excellent, gave an indication of the importance of being spoken to directly when he said:

I thought that [doctor's rounds] was brilliant because um, they were talking to me as well as the nurses and themselves. They were making sure I knew what they were talking about and if I was alright.

However, when staff communicate through parents, children and young people may be less likely to rate care as being satisfactory and to adhere to treatment (Pantell and Lewis, 1993; Holtzheimer et al., 1998). This was evident in this study and is best explained by one of the young people who rated some aspects of care as not good enough:

B: I think it would have been better if they would have addressed it more to me, because they seemed to be talking more to my dad than what they were to me. Like telling my dad what's going on and not me.

T: What else? What about the painkillers that were given to you before you were discharged [and letter to dad]?

B: Well, I would say that is not good enough again, because it seemed to be more telling my dad what they were for than what they were to me.

### **Choice**

More than half of all the participants (and specifically three-quarters of the Year 5/6s) picked out instances in the story where choice had been given as being one of the best aspects. In contrast, situations where choice was not given were not necessarily recognized so frequently. This suggests that when choice is *not* given then this is *not* noteworthy, but when it *is* given it is something to be pleased about. Perhaps, having choice is something that eludes many 9- to 11-year-olds so situations where choice is given are novel and therefore stand out more. So, when choice is given, that is special in their eyes. In other words, the experience exceeds their expectations and leads to a positive evaluation. But when choice is not given it is not necessarily going to be seen as contributing to poor quality care. Children and young people thought it was good to have some degree of choice as they did not like '*being told what to do*' (Year 5) and '*being asked what you wanted*' (Year 6) was appreciated. On the other hand, '*choice isn't number one because you don't always know what's best for you*'. So, while the children and young people in this study identified choice as important in their care, they did acknowledge that it is not always possible or always appropriate.

### **Friendly staff**

Participants selected instances when staff were being friendly in roughly equal measure to those instances where staff were not so friendly. Doorbar (1996) also identified friendliness as one of the dimensions that contributes to the quality of communication and key to the quality of health care received. Ramm et al. (2004) identified the need for doctors and nurses to be friendly and reported this as a key finding from the focus groups held as part of the development of the NHS Survey. Neither of these studies gives any indication as to what might constitute 'friendliness' from a child's perspective. Exploring reasons for citing these instances as being either a best or worst aspect of care can help to develop a more rounded understanding of what being friendly means to the children and young people when they are in hospital.

Staff who were being friendly took time to sit and chat, cheering people up with smiles and humour, paying them attention and '*checking on them frequently*'. Participants talked about staff being really nice, helpful, kind, comforting, and caring. To be caring in a friendly way requires the carer to acknowledge the value of the person being cared for. It is about being recognized and being made to feel at ease. Staff who were not being friendly were described as being '*horrible*', '*rude*', '*unkind*', '*nasty*' and '*impersonal*'. Comparisons were made between staff in the story who did not mind doing things for their patients, and those who gave

the impression that they did not want to be bothered. It was interesting that participants commented on the friendliness *between* members of staff, and how the atmosphere that this created impacted on how patients felt. Clearly the attitude that staff have towards their young patients and each other is crucial to perceptions of good quality care for children.

### **Respect**

When respect was afforded to the child in the story, very few children and young people picked this up as being one of the best aspects of care. However, when respect was *not* afforded, three-quarters of the participants picked those instances out as being one of the worst aspects of care. Some of the worst things were '*being treated like I was stupid*', '*being ignored*' and '*being patronized*'. Again, the results show an imbalance in that respect seems to be assumed to be present, and only when it is absent is it worth commenting on, a possible case of experiences falling short of expectations. Thus, when disrespect for them as persons is evident during periods of hospitalization, the children and young people in this study would be more likely to rate care as poor. In a study of the causes of dissatisfaction with hospital-based care, Rogers et al. (2000) found that expressions of dissatisfaction arise from a sense of being devalued, dehumanized and disempowered. They suggest that the promotion of patient autonomy and dignity/respect (one of the central tenets of palliative care) would do 'much to enhance satisfaction with healthcare for all patients' (p. 773).

### **Towards a hierarchy of quality indicators?**

An analysis of the data from the ranking exercise showed that it was possible to rank the five characteristics in order of importance to the children and young people in the study. Nearly three-quarters of the participants ranked good technical skills as the most important characteristic. At the other end of the scale, a similar number ranked explanations and choice as the least important. Though one other study has offered quality criteria from children's perspectives (Mitchell and Sloper, 2003), they have not been assembled in any order of priority. Although no firm conclusions are drawn from this, the Research Team concluded that it may be interesting to pursue the possibility of a hierarchy of quality indicators of care.

## **Conclusion**

This work complements previous research and adds new knowledge that can guide professionals in their quest for quality care for their young patients. From the perspective of the children, quality had something to do with identifying

the things that went well for them and the reasons why this was so. In comparison, they were very clear about things that constituted poor care. The children in this study did not need an explanation about standards; they based their views on their expectations. That is, they knew if care did/would not meet with their expectations. It was their expectations that framed their perceptions and led them to make judgements about whether care was good enough or not. So, even if they had not been in hospital before, they had certain ideas about what to expect and measured quality against them. Although children and young people in the study each gave their own subjective view, it was possible for the Research Team to draw out five characteristics in order of importance – *technical expertise, friendly staff, respect, explanations and choice* – that have the potential to make a significant contribution towards the quality of care received by children during a hospital stay.

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