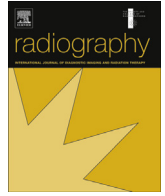




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Case report

Even if the differences were small they were noticeable: Experiences of being a member of a Children's Council in a children's hospital

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ABSTRACT

Background: There is a requirement for health professionals to engage with children in matters relating to their health care and in the evaluation of service delivery. One approach is via a Children's Council within a hospital. Although relatively new to the UK, Councils have been established longer in children's hospitals throughout North America.

Main aim: This study sought to explore the experiences of a child Council member within a large children's hospital and assess if a Council was a suitable method for radiographers to engage with children to evaluate services.

Method: A single case qualitative study was carried out using a semi-structured telephone interview. The participant has attended a children's hospital since birth and been a Council member from age eight to when his care was transferred to adult services. The interview was audio-taped and the full transcript produced and analysed following the recommendations of Reissman (1993).

Main findings: The participant was eager to share his experiences of Council membership and the process by which projects were identified and carried out to their ultimate success or otherwise. Duties of Council members were discussed, engagement with health professionals described, specific topics related to adolescent care in a children's hospital explained and the life lessons learned reported.

Conclusions: This study provides a unique insight into the experiences of a member of a Children's Council. The effectiveness of this model to establish engagement with younger patients is demonstrated and could provide a method to establish engagement between radiographers and children.

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Background

Although the origins of the phrase 'children should be seen and not heard' have been lost in the mists of time, from the Victorian era to relatively recently the common use of this phrase perhaps reflects the limited value placed on children's views on any topic or decisions relating to their lives. Since late in the 20th century, this attitude towards children has been changing and the voices of children and young people have been increasingly sought in the development of policies, service planning, delivery and evaluation of children's services such as in the areas of social care and education.¹

Engagement of children in matters relating to health care

As early as 1959 the Platt Report² stated children and young people (hereafter described as children) could no longer be seen as little adults and should have their specific health needs and requirements addressed. There was a clear need to establish engagement with children in all matters relating to health care and service delivery and evaluation of health services.³

The real catalyst for engagement with children in health care was the United Nations Children's Fund (2003)⁴ which stated that health services for children should be delivered in a way that is acceptable to children. This was further endorsed by the development of the National Children's Framework.⁵ In addition, the United Nations Children's Fund⁴ charged all health professionals with the task of encouraging children to make their views known on issues which relate to their health care.

Direct engagement with children in matters relating to their health has taken longer than other areas such as education. This

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may be because traditionally, any evaluation of health related issues has not been carried out directly with the child but through adults acting as an advocate (or proxy) on their behalf. The difference between evaluating a service on behalf of a child (i.e. child perspective given by a parent or guardian and having the child's interest at heart) and a child's perspective (told by the child themselves) has been eloquently described and the subtle difference between both points of view explained.⁶

Another argument against engaging directly with children was related to their supposed inability to give their opinions. This viewpoint has now been challenged⁷ with children being considered able to articulate their opinions on the provision of service delivery from a pre-school age as long as the methods of enquiry are adaptable and age-specific.⁸

So why is it important to hear the children's voice?

Children are major users of health care. With less than 20 specialist children's hospital across the whole of the United Kingdom, the bulk of childhood hospital attendances will be at local hospitals primarily designed to deliver adult health care.⁹ The availability and quality of children's health care in non-specialist hospitals has been questioned and it can be problematic for staff to maintain their competencies in dealing with children⁹ due to the varying number of children attending.

Engagement with children

There is therefore a need to evaluate the services provided for children and establish if they are responsive to children's needs.¹⁰ Shier (2001)¹¹ developed a five level model to encourage health professionals to engage in issues relating to children. These levels are i) children should be listened to; ii) supported to express their views; iii) their views should be taken into account; iv) children to be involved in the decision making process; and v) share power and responsibility for decision making. Children should also participate in clinical audit^{12,13} to establish their views in relation to satisfaction with their care.⁶

Enabling children to have a 'voice'

In order to explore the child's perspective of their care, children need to be given a voice to enable them to exercise their right to express their views, needs and opinions. Many agencies and Charities have described methods to enable engagement with children^{15,16,17} and these include the use of non-traditional methods of enquiry which can make the process more fun for children¹⁸ but can be challenging for the inquirers.¹⁹

One method advocated to evaluate services and make changes in the hospital setting is the presence of a Children's or Youth Council. The process of establishing such a group is challenging but changes can be made to service delivery as a direct result of such a group.¹⁴

A search of the websites of Children's Hospitals sought to explore the existence of Children's Councils. A number of sites gave no description of such a Group and if one did exist, different models were indicated (e.g. a 'stand alone' Council with facilitators or a number of child patient representatives attending the formal Health Board meeting).

Examples of the evaluation work carried out by Children Councils were described and included members being 'mystery patients' within hospital environments, such as reception areas, resulting in reports being written by the children with recommendations for improvements.²⁰ Alder Hey Children's Foundation Trust²¹ describe having their first Children's Council of 10 children

(ages between 10 and 19 years) in order to 'make consultation a reality'.

Hospitals with Children's Councils indicated their involvement in the development of new children's hospitals contributing 'ideas, hopes and aspirations' for their new hospital.²² This reflects recommendations made in 2008²³ to consult with children when new hospitals and services are being developed. However, the evidence from the websites suggests that these Councils may not continue after the opening of the hospital as reports of meetings after completion do not continue.²⁴

Rationale for paper

Although relatively recently established in the UK a number of hospitals in North America have had Children's Councils for a number of years. A literature search on Medline and CINAHL (2000–2013) indicated that although many papers and policies describing the need to engage with children, and encouraging health professionals to give children a voice to evaluate healthcare, do exist, there are few papers which describe this in reality. While papers explain the process of establishing Children's Councils,²⁵ there is a dearth of papers describing the experiences of Council members in their own words whilst serving on an active Children's Council.

Importantly, previous research has indicated a lack of engagement by radiographers with children²⁶ in matters relating to service development and evaluation. This work led to the development of Practice Standards for the Imaging of Children and Young People (2009)²⁷ which includes a recommendation to obtain the views of children, young people and parent/guardian on service provision. Radiographers may feel there are limited opportunities for this to happen but engaging with a Children's Council may be a possible way to start this.

The aim of this study was therefore to develop an understanding of the experience of a child as a Council member. The main objectives were to explore: i) their perceptions of their role; ii) the experience of being an active Council member; iii) their perceived successes and failures; iv) whether any life skills and lessons had been learned during their time on Council; and v) if the work carried out by a Council could facilitate engagement between radiographers and children.

Method

A single case qualitative study was carried out in order to capture the 'how and why' of the issues to be explored for the single individual.²⁸ This approach is acknowledged to be exploratory and limited to the experiences of the one participant and therefore findings cannot be generalised or considered reliable in the broader context.^{28,29} A semi-structured interview was carried out which drew on phenomenological methodology as discussed by Marshall and Rossman³⁰ to provide a unique insight into the experiences of a child as a Council member.

Participant

The participant is known by the author who has shared his experiences over a number of years. Indeed it was listening to his experience that was the catalyst to looking more closely into the work of Children's Councils in hospitals and exploring the possibility of whether radiographer engagement with such Groups could be a route to engage with children in the evaluation of imaging services.

The author asked if he would be willing to share his experiences via a telephone interview and allow the author to include them in a

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