

Introduction

My role as an Advanced Nurse Practitioner in adult acute medicine had involved the clinical assessment and management of adult patients and as a lead member of the cardiac arrest team. Regularly in practice children were present visiting an adult relative. Many colleagues were unsure how to approach these children and there was a paucity of guidance for our clinical setting.

This participatory action research (PAR) PhD study aims to identify and critically explore the issues surrounding children visiting adult relatives who are patients in a large teaching hospital in the UK.

The primary objectives are;

- to increase understanding into how staff could be better prepared to support children and their families when visiting acutely ill adult patients at the hospital
- to explore the feasibility for staff to change current practice and improve the experience of both child visitors and their families.

With importance being placed upon children's participation in healthcare research (Fleming and Boeck, (2012), children and young people (n = 37) have been engaged in two elements of the research;

1. Prior to the research consultation focus groups were held to inform the research design (n = 23)
2. A local college participated in the exploratory stages of the research (n = 14)

Figure 1 - Including children in the research

- Not when visiting relatives at the hospital,
- After they have seen their family member if the child is emotionally stable
- Don't ask them a questionnaire, just a few questions
- After discharge would be better, but not if the relative had died
- Thought it best to speak to different groups, but be careful as some children may not wish to talk about their experiences
- They might not want to talk about it in a classroom setting so smaller groups might work better
- Don't visit schools and pick out kids who have visited adult relatives as it is a sensitive topic
- Children probably won't be interested

References

Butler, V. (2012) An exploration of how ethics inform the design of social research with children under 11 years of age. IN J. Fleming, & T. Boeck, (Eds) *Involving children and young people in health and social research*. London: Routledge.

Fleming, J & Boeck, T (2012) (Eds) *Involving children and young people in health and social research*. London: Routledge.

Liamputtong, P (2011) *Focus group methodology. Principles and practice*. London: Sage

Read, S (2013) Facilitating bereavement support for people with intellectual disabilities in England IN J. Hockley, K. Froggatt, & K. Heimal (Eds) *Participatory research in palliative care*. Oxford: Oxford University Press.

“Good research practices involve users and carers across all steps of the research continuum” (Read, 2013, p86)

Consultation Informing the research design

Methods

Contact was established with the West Midlands Medicines for Children Research Network (MCRN) User Involvement Coordinator who asked the Young Persons Advisory Groups if they would provide consultation for the PhD research proposal.

Two consultations were held and the young people were asked to;

- discuss past experiences
- provide their suggestions of what is required by children visiting adult relatives in hospital, particularly relating to communication
- explore whether children visiting a relative should be approached by the researcher
- discuss the participation of other children's groups (MCRN, schools, clubs) in the study to provide feedback on plans/leaflets.

The first consultation was a focus group of young people from the West Midlands MCRN Young Persons Advisory Group (n=15; three boys and 12 girls, aged between 10 and 17 years). The second focus group incorporated members of the London and South East MCRN Young Persons Advisory Group (n= 8, four girls and four boys aged between 8-17 years).

Results

The experiences of visiting adult relatives at the hospital reflected the literature.

They discussed what they thought the components of an appropriate research design would be in relation to children and young people's involvement (Fig 1)

This consultation feedback was valuable in guiding the research methodology and design. The decision was made not to approach children at the hospital, but to work with the hospital staff and consider involving children and young people in the evaluation stages.

Figure 2 - Experiences

- They didn't really talk to me, it was just to my Dad
- Parents hold back things.
- You had to find out for yourself
- You feel patronised
- It's like they don't think that we have a right to know, it's like only the parents do
- Some of them can be quite intimidating – walk up to the bed and give you the look
- You need to know what to expect
- You're not bothered if it upsets you in a way. You want to know what's going on
- If they ignore you, you think they won't answer

Collaboration Young person's focus group

Methods

During Phase 1 of the research Registered Nurses identified that there was local need for resources and education for both staff and visitors. Students, aged 16-19 years, from a local college requested to participate in the project by designing these resources. They also asked if they could have their own focus group in order to reflect on their work within the project and to provide a young person's perspective upon local services.

The focus group took place at a local college. 14 young people took part (12 female and 2 male) with the support of 2 college tutors.

The group were asked to discuss;

- past experiences of visiting adult relatives in hospital
- their experiences of finding age appropriate information and developing resources
- what they thought was required at the hospital to support children and young people when visiting ill relatives.

Results

Some perspectives and views confirmed the findings of previous research (Figure 2)

Other views were unexpected or detailed issues that had not been considered. They were conscious of how busy hospital staff were and considered that strategies such as Facetime could help to reduce visitor numbers or queries directed to nursing staff (Figure 3)

Figure 3 -What would help

- Availability of Skype or FaceTime.
- When asked about a designated practitioner for teenagers they responded – no, they all should have a basic way of how to talk to people, of how to describe everything to us.
- If someone comes and speaks to you. I might have thought of a question - I could have asked her if they acknowledge me

Reflections

Engagement of children and young people in research is an important and expanding area, where care must be taken in relation to the research design, the research process, and the preparation of those children and professionals involved.

Support from the college tutors ensured that the 'comfort level' of the participants was monitored (Liamputtong, 2011), and helped to redress the power imbalance between researcher and participants.

“Children are a part of the social world and without their perceptions and experiences being documented, we gain a partial view, and an inaccurate perspective” (Butler, 2012, p72)