

# Children should be more involved in healthcare decisions that affect them

April 19 2017, by Imelda Coyne



Credit: Andrea Piacquadio from Pexels

Few people would disagree that children have a right to participate in matters that affect them. But in hospitals this right seems to be waived. My research at hospitals in Ireland revealed that children <u>find it difficult</u>



#### to have their views heard.

The <u>children</u> said that doctors and nurses were "nice" and "kind", but some tended to carry out medical procedures without seeking their opinions or telling them beforehand. Some parents helped children to be included in talks about their care, but other parents answered questions on their behalf, told them to stay quiet and withheld information from them. Some parents also told their child to stay quiet and not annoy the doctor or nurse. Being excluded from discussions made some children feel sad, frustrated and angry. As one 14-year-old girl put it: "It made me feel like a piece of machinery; they weren't actually talking to me."

## Big and small decisions

Children tend to see decisions as being big or small. They generally accept that adults make the "really big" decisions and they trust them to make the right call. Children tended to trust their parents as they have their welfare at heart, and they believe that <a href="healthcare professionals">healthcare professionals</a> know what the best treatment is as they are the experts. Nevertheless, children said that they would like to be included in discussions about decisions that affect them. They also expressed a desire for adults to use simple words – not medical jargon.

According to children, the "small decisions" are those that focus on the way the nursing care, procedures and tests are done to them. For many children, though, these are <u>important decisions</u> because having choices makes it easier to cope. Inclusion in decisions, makes children feel happier, respected, less anxious and more prepared. Most children, regardless of age, prefer to share <u>decision</u>-making with their parents and healthcare professionals rather than have sole responsibility.

### Respecting human rights



Children and teenagers need to be involved in decisions as it respects their rights as human beings and makes it easier for them to cope with receiving care in <a href="hospital">hospital</a>. Being in hospital can make children scared and anxious, but they are less likely to be distressed if they are prepared for what is going to happen to them.

Drafted by the UN nearly 30 years ago, the <u>Convention on the Rights of the Child</u> states that children have the right to be heard in all matters affecting their lives. Although there has been significant efforts to respect and promote the rights of children, they still encounter barriers to having their views heard in decisions that affect them.

Healthcare professionals and parents don't always agree on the extent to which children should be involved in making decisions about their treatment. Doctors and nurses want to provide the best care and treatment but worry about children's mental ability and emotional maturity to participate in decisions. As a result, some healthcare professionals restrict the involvement of children in decisions that could influence the outcome of treatment for the worse.

Likewise, parents want the best for their child. They want to make the hospital stay easier for the child and for their child to get better and return home. Parenting practices have changed greatly over the past 30 years, and we now know that parents tend to listen more and include their children in everyday decisions in the home. In the hospital, many parents think it is important to involve children in decisions to promote self-esteem and well-being. But some parents feel they should protect their child from potentially distressing information or difficult decisions, so they restrict their child's involvement. They think that the child has enough to cope with, so they filter the information to avoid causing further distress.

However, we should not be overly critical of parents and healthcare



professionals who exclude children from <u>healthcare decisions</u> as these decisions are not always straightforward and can vary a lot depending on the situation. Children often want to participate in discussions about their care but would rather not bear full responsibility for decision making.

When we talk about <u>healthcare</u> decisions most people think of major decisions that make the headlines, such as end-of-life decisions or legal capacity to consent. For children, though, it is about taking part, voicing preferences, being listened to and being heard in the decisions that affect their lives in hospital. These may be simple, but they can make a huge difference to children.

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