

The importance of including both a child perspective and the child's perspective within health care settings to provide truly child-centred care

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Abstract

The UN Convention on the Rights of the Child (1989) asserts the right of every child to self-determination, dignity, respect, non-interference, and the right to make informed decisions. The provision of quality care in health services tailored to children's preferences means that health professionals have a responsibility to ensure children's rights, and that the child is encouraged and enabled to make his or her view known on issues that affect them. This paper will help illuminate and differentiate between *a child perspective* and *the child's perspective* in health care settings. The issues are supported with research which illustrates the different perspectives. Both perspectives are required to perceive and encounter children as equal human beings in child-centred health care settings.

Keywords

child, child-centred, healthcare, perspectives, quality, rights

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Introduction

The United Nations Convention on the Rights of the Child (1989) recognizes children's (0–18 years old) rights to protection, and the promotion of their well-being, as well as participation in matters that affect their lives. The Convention clearly states the right of every child to self-determination, dignity, respect, non-interference, and the right to make informed decisions. More recently, in 2002, the United Nations held a Special Session of the UN General Assembly on Children, at which the nations of the world committed themselves to a series of goals to improve the situation of children and young people (UN General Assembly on Children, 2002). It is the United Nations Children's Fund's belief that children need to be encouraged and enabled to make their views known on issues that affect them and that the goals of 'A World Fit for Children' will only be accomplished with the full participation of children and young people (The United Nations Children's Fund, UNICEF, 2003). The provision of quality care in health services tailored to children's preferences means that health professionals have a responsibility to ensure children's rights, and that a child is encouraged and enabled to make his or her view known on issues that affect them. Thus there is a need to reflect on and illuminate the difference between a *child perspective* and the *child's perspective*.

According to Sommer et al. (2010), a *child perspective* is characterized by the adults' outside perspective on children's conditions, experiences, perceptions and actions, with the individual child and his/her best interests in mind. A *child's perspective* is characterized by the child's insider perspective on the conditions, experiences, perceptions and actions, based on what he or she find as important. Both perspectives are required to perceive and encounter children as equal human beings. However, as Archard (2004) argues, this is a contentious issue because who knows what the child's best interest in a situation is? Is it the adult's or the child's? Conflicting interests can occur between the provisions in the United Nations Convention on the Rights of the Child (1989). There is a clash between the child's need for protection and the child's rights of participation (making his or her voice heard, having their own opinions and making their own decisions).

A child-centred approach implies that health professionals need competence in the areas of children's development, life conditions in general, and knowledge about the specific child in the specific situation. They further need competence in the field of children's rights. Health professionals should be aware of how they use their child perspective, including these competences, in a situation while considering the child's perspective in the same actual situation. The opportunity to consider the adult and professional child perspective and to achieve the child's perspective in a situation is dependent on the adult's skills in perceiving and understanding the child's world (Sommer et al., 2010).

This paper will help illuminate and differentiate between a *child perspective* and the *children's perspectives* in health care settings. The issues will be supported with research which illustrates the different perspectives. The paper will conclude with an argument for a child-centred approach in health care settings.

A child perspective

Research conducted in the area of family-centred care and family involvement can be viewed as having children's best interest in mind and grasping the child perspective without involving children directly. Family-centred care in paediatric care is defined as 'care that is led by parents, with the nurse acting as a consultant, encouraging open and honest dialogue with the family' (Shields et al., 2007). The Institute for Family-Centered Care (2005) defines it as an approach

to the planning, delivery and evaluation of health care that is governed by mutual beneficial partnerships between health care providers, patients and families. The institute applies family-centred care to patients of all ages (Institute for Family-Centered Care, 2005). In paediatrics, family-centred care has been considered the best way to provide quality care to children in hospital, despite a lack of evidence about its effectiveness (Carter, 2008; Shields et al., 2007). However, in a review, Davies (2010) demonstrates changes in attitudes about parental presence, family-centred care and family involvement, and how parents and families participating as caregivers have been promoted over the last five decades. International research within the area has had a considerable effect on the quality of children's nursing due to its knowledge about how professionals encounter families and their wish to encourage parents to participate in their child's care (Coyne, 2006a, 2008b; Paliadelis et al., 2005; Söderbäck, 1999; Söderbäck and Christensson, 2007), as well as knowledge about parents' experiences that their involvement is important for their child's recovery (Coyne, 2006a; Kristensson-Hallstrom, 1999; Söderbäck and Christensson, 2008; Ygge and Arnetz, 2004). It is evident in the research that nurses use various methods to interact with families in order to deliver care that is in the best interests of both the child and the family. Overall it is clear that professionals in children's nursing sometimes assume that parents will continue to care for the child while in hospital, providing care similar to that in the home.

Research by Vessay (2003) demonstrates a child perspective when focusing on the factors known to influence children's reactions in the health care environment. Here the child's developed competence, biological factors as inherited characteristics and state of health, as well as ecological factors such as family and health care environment are identified as important factors for understanding the child's situation. Ecological factors can be manifested in the overall ideology of children's rights in a health care organization because it has to do with the space each child is given in the organization.

Other research which can be viewed as having a child perspective describes knowledge about children's developmental state, maturity and age to support their right to be informed (Edwinson Månsson, 1992). Further research which reveals a child perspective highlights children's rights as informants and participants who can take part in information exchange in care situations (Coyne et al., 2009). There is also a child perspective when describing the interaction between child, parents and health professionals (Coyne 2006a, 2008a), and when describing the information exchange between health professionals, parent and child (Mårtensson et al., 2007; Tates and Meeuwesen, 2001). Mostly this is done to respect the child's best interest by having the child's rights in mind. But in practice, adults with the child's best interests and rights in mind can also act and take decisions in a situation without finding out the *child's perspective* and the *child's competence*. Coyne (2008a) reports how health professionals are aware of the importance of consulting with children but that they do not always seek or acknowledge children's views. This corresponds with Alderson (2007) who states that the degree to which children are able to participate in a situation is dependent on how health professionals perceive the child's capacity and the extent to which they elicit the child's perspectives. Therefore, as Jolley (2006) points out, adults must capture and learn the way a child experiences and understand the situations from his or her perspective. Furthermore, Shields (2010) argues there is a need to deliver care to children through an approach other than family-centred care.

The child's perspective

Conducting research *with* children is essential if we want to find out their perspectives. Traditionally the adults' view of children's perspectives has been sought, with parents generally acting as proxies

for children. However adult proxies' views of children's experiences may differ quite markedly from children's own views and in some situations may be flawed or inaccurate. Hence researchers are increasingly recognizing the importance of directly recording children's own perspectives (Coad and Shaw, 2008; Greig et al., 2007) which is contributing to a better understanding of children's experiences and needs.

The National Youth Agency (NYA) and the British Youth Council (BYC) surveyed statutory and voluntary sector organizations in England in order to establish the extent to which children are involved in public decision-making (Oldfield and Fowler, 2004). They found that the level of participation was greatest in organizations that had a specific remit to work with children but more limited in health and criminal organizations. In Sweden, the Ombudsman (Barnombudsman, 2009) carried out a survey among children (age 11 and 14) about their perceptions of being respected by adults within different sectors of society. The health care services received the least positive response. The children stated they were not respected or taken seriously when they had something to say. Children's experiences in health care of not being listened to, or not being supported, and their desires to have more to say are reported by several researchers (Coad and Shaw, 2008; Coyne, 2006b; Runeson et al., 2002). Bates and Meeuwesen (2001) analysed video observations of doctor–parent–child medical encounters in the Netherlands and found that in most consultations both doctors and parents displayed non-supportive behaviours towards children's participation. These studies demonstrate the need to consider the children's perspective to improve the way they are encountered and to accord them their rights.

Research from *children's perspectives* is captured when exploring their expressions, experiences, perceptions and understanding (Sommer et al., 2010). In their study, Carney et al. (2003) sought children's experiences of fears during hospitalization. The children (age 13–17) identified a range of fears connected to separation from their family, the unfamiliar environment, loss of self-determination, and medical examinations and treatment. Salmela et al. (2010) investigated what strategies children used to deal with fear in hospital and found that the children talked about having their parents and other family members present. The children also spoke of other positive images they had of hospitalization which included humour, toy and play. Coyne et al. (2006) found that the children could relate varying experiences of being consulted about their care and treatment. The children's own opinions and views were, however, found to be underused because the children's involvement seemed to be dependent on the child's cognitive maturity and being defined as a rational subject. Runeson et al. (2007) also reported that children admitted for a planned diagnostic procedure reported that they were not very well informed and did not participate fully. From children's accounts, we know how living with short-term illness and or with several diseases affects their everyday lives. Forsner et al. (2005) describe how children talked about being lost, hurt and in need of comfort. Guell (2007) and Protudjer et al. (2009) described how the children exert themselves to achieve normality by taking control over their lives. Stewart (2003) identified similar findings when describing how children undergoing treatment for cancer described they got used to their situation and focused on the ordinary and routine. To exhibit and include *children's perspectives* helps professionals to ensure that the quality of care is enhanced and supported with well developed quality indicators (Pelander et al., 2009).

These above studies were held with children from 5 to 18 years of age. *Young children's perspectives* in research are still under explored. Research with younger children needs methodologies which sensitively uncover their expressions and views. Video recording children (3–4 years old) in health care situations was used by Harder et al. (2009; 2011) and by Söderbäck (forthcoming). The focus was on uncovering children's bodily and verbal expressions to explore their actions and how

they were involved in various care procedures. The 3-year-old children (Harder et al., 2009) demonstrated how they progressed through various states of being when participating in an assessment of speech development: from a state of getting ready, to a state of being ready and further to a state where the children strengthen themselves. Further, the children's states of being were coloured by the states of not being ready or being averse. The 4-year-old children (Harder et al., 2011) demonstrated their perspective by using affirmative or delaying negotiation strategies to influence and deal with a situation of assessment of motor and cognitive functions. Söderbäck (forthcoming) found how young children undergoing a venepuncture procedure demonstrated their engagement. These young children expressed actions of watchful, evasive, curious, adaptive and enforced engagement when interacting with their parents and the nurses who participated during the procedure.

The above studies are viewed as taking the young children's perspectives into consideration. However, it is important to realize that when grasping young children's bodily and verbal expressions it is an adult researcher who captures and interprets the child's perspective in a situation (Sommer et al., 2010). To be trustworthy, this interpretation of a child's perspective needs sensitive deliberation in the context of the actual situation. The circumstances in an actual situation will influence the child's expressions and thus how they are portrayed. In the adult's interpretation it is important to take into account the totality of the situation in which the child acts with other participants, not least the researcher's own understanding and child perspective (Halldén, 2003).

Towards a child-centred approach

In health care settings interactions between the child and adults, his/her parents or other family caregivers and health professionals always occur. In these interactions the child will contribute as an actor and participate in the construction of what will happen. All the experiences the child has will further influence actions in the future, because how a child acts in any situation depends on the child's competence and earlier experiences of various everyday situations (Sommer et al., 2010). Acknowledging and respecting children as actors and promoting their opportunities to contribute to health care situations together with family and health professionals means that a child-centred approach is essential. A truly child-centred approach includes both the adult's *child perspective* concerning the children's best interests in terms of care and the *child's perspective* with respect to his or her preferences.

From the research presented it is evident that parental or family presence in health care settings is important from both the adults' child perspective and from the children's perspective. However, ensuring children's rights will also bring about a disparity between what is in the child's best interests from the adult's child perspective and from the perspective of the child him/herself. Who knows the child's best? Since health care procedure or situations are complex, the health professionals and parents' perspectives on what is in the child's best interests might differ and not harmonize with the child's own perspective on what is in his/her best interests. Furthermore, a health care procedure or situation might be conditioned by the fact that health professionals will adopt the belief that it is the parents who are the experts on their own child's perspective. The difference in age and authority between children and adults, and children's dependency on adults further contributes to an uneven power relationship. This might result in situations where health care professionals and/or parents regard children as my/our children (Shields et al., 2003). 'Owning' a child is never compatible with children's rights. When health professionals pass responsibility to the parents it does not always benefit the child and they could be abdicating their

professional responsibility to respect and give due weight to the child's perspective. A *child-centred approach* raises three important questions:

- Should parents make decisions regarding their children's health without considering the child's right to participate?
- Should children be examined and treated despite their reluctance to the procedures?
- Should health professionals make decisions not fully understood by children and/or parents?

Capturing the child's perspective requires adults, parents and health professionals to be attentive, sensitive and supportive of each child's expressions, experiences and perceptions. A model to encourage health care organizations and health professionals to support children's right to participate in topics that concern them and to achieve the child's perspective is offered by Shier (2001). This five-level model will be a useful aid to ensure that:

1. irrespective of age the child is listened to
2. the child is supported in expressing his/her views
3. the child's views are taken into account
4. the child is involved in the decision-making process
5. the child can share power and responsibility in the decision-making.

This last level is not to leave the responsibility to the child; instead it is a way of sharing responsibility.

Further, interactive communication programmes could be useful for the child and for the adults to raise awareness, enhance communication and help to share understandings and needs. Ruland et al. (2008) have used such an interactive communication programme (SiSom) with children to take into account the child's perspective in relation to the evidenced knowledge of symptoms associated with cancer.

To conclude, treating children with dignity and respect, acknowledging their competence and supporting their actions are of prime importance in today's health care settings, according to the UN Convention on the Rights of the Child (1989). The provision of quality care in health services tailored to children's preferences means that health professionals have a responsibility to ensure children's rights, and that a child should be encouraged and enabled to make his or her view known on issues which directly affect their life. The approach of family-centred care needs to be redirected towards a *child-centred care approach* which incorporates the rights of the child to participate in all aspects of health care delivery in conjunction with the need of their family.

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