Comforting measures described by staff working in paediatric units


Abstract

Aim Children with cancer identify staff members, who work with them in paediatric units, as their most important comforters. This study aimed to shed light on how those staff members deliver this comfort.

Methods Semi-structured interviews were performed and the content then analysed. Nine families (n=9) and eight staff members (n=8) participated in the study.

Findings The staff described caring for the children and the whole family. They implemented certain comforting measures with the child, and described how they provided support to parents. Staff described how they felt comforted by relating to the children they were caring for.

Conclusion Staff working in paediatric units develop good relationships with children and parents and comfort them using methods described in the literature. The quality of the staff’s positive relationships with the children marked all their actions.

Keywords cancer, child health, comforting measures, family, paediatric nursing

CHILDREN WITH cancer often undergo painful and distressing treatment (Woodgate 2006, Griffiths et al 2011, Hildenbrand et al 2011). In stressful care situations, children and their families need to be comforted. Kolcaba (2003) defined comfort as ‘the immediate state of being strengthened through having the human needs for relief, ease, and transcendence addressed in four contexts of experience (physical, psychospiritual, sociocultural, and environmental)’. One important aim of nursing is to relieve patients’ suffering and provide comfort (Kolcaba 2003).

Literature review

The literature reviewed for this study described various means of comforting children, for example being attuned to cues of distress and implementing comforting measures, such as listening, talking and touching, being kind, showing children respect, playing and developing a trusting relationship (Kolcaba 2003, Schmidt et al 2007, Cantrell and Matula 2009, Lu et al 2011, Reich 2012, Ångström-Brännström et al 2013, Carnevale and Gaudreault 2013, Ångström-Brännström and Norberg 2014).

Ill children often mention their parents as primary sources of comfort (Ångström-Brännström et al 2008, Lu et al 2011). Parents may act as a bridge between the nurses and the children, and nurses can empower parents to comfort their children (Kars et al 2008). Children also consider siblings, grandparents and friends as comforters (Carnevale and Gaudreault 2013).

In interviews carried out in a previous study, children with cancer had spontaneously described who, among the staff working in children’s units and who cared for them, were their most important comforters (Ångström-Brännström and Norberg 2014). The aim of the study was to discover how these particular staff members described comforting.

Method

This article reports one part of a larger project about experiences of comfort for children with cancer and their families. Nine families (n=9) with children with cancer in a paediatric oncology ward in northern Sweden participated in the study. Interviews with parents and children about their experiences of finding comfort have previously been reported by Ångström-Brännström et al (2010) and Ångström-Brännström and Norberg (2014), respectively. In this study, the experiences of staff working in paediatric units when
comforting children with cancer are reported. The study is qualitative and descriptive and has an inductive approach.

Data collection
All of the staff members mentioned as most important comforters by the children were asked to participate in the study. Although we did not tell them which child had praised them, all guessed correctly. All eight staff members – five registered nurses, one assistant nurse, one teacher and one preschool teacher (seven females and one male) (n=8) – agreed to participate. We refer to them as the ‘important comforters’ (ICs).

The first author, a nurse with experience in working with ill children and not a staff member, interviewed the participants at a time and place decided by them. They were informed that a child – kept anonymous – had mentioned them as an important comforter during her or his cancer treatment. They were invited to talk about their experiences of comfort when working with children with cancer.

The interview started with the question: ‘Please, tell me about a situation in which you have comforted a child.’ The open-ended interview questions explored comfort from the participants’ perspectives and their experiences of comforting children with cancer.

Follow-up questions, such as ‘What do you mean?’ and ‘What did you think/do?’, were also asked. The tape-recorded interviews lasted 60 to 80 minutes, and were transcribed verbatim. Pauses, sighs, laughter and silence were marked. Interviews were conducted in Swedish and, after being analysed, citations from the interviews were translated into English.

Analysis
An inductive qualitative content analysis was performed (Graneheim and Lundman 2004). The interview text was read through several times for a sense of the content. Then it was divided into ‘meaning units’ comprising sentences or phrases with similar meaning. The meaning units were condensed, compared and assigned a code. The codes were compared, discussed and subcategories were formulated and abstracted to four categories representing the content of the interviews (Table 1). The process was not as linear as the table suggests. There was more than one meaning unit per subcategory and more than one subcategory per category.

Ethical considerations
The staff were informed in writing and orally about the study and that they were free to withdraw from the study at any time before the interviews were analysed, without stating a reason. They were assured confidentiality and anonymous presentation of findings and all consented to participate. The Ethics Committee, Umeå University, Sweden approved the study (05-017M).

Findings
The findings show that the staff working in paediatric units who had been identified by children with cancer as their most ICs describe comforting children as listening and spending time with children and parents, and that these ways of offering comfort differ from person to person. When children and parents express suffering, the ICs can share their suffering and provide comfort. The four categories are presented in this article, together with citations from the interviews, marked with

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<th>Meaning unit</th>
<th>Condensed meaning unit</th>
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<td>‘Simply staying there and not being able to say “It’ll be all right, you’ll get better” – you can’t even promise that, all you can do is be there’</td>
<td>‘Staying there saying “You’re going to get better” – you cannot promise that’</td>
<td>Being at the child’s side</td>
<td>Sharing the child’s suffering</td>
<td>The important comforters comforting the children</td>
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<td>‘So … what I feel … and perhaps more and more now … I mean, seeing the children and having time for them and, you know … seeing the whole family, I mean, how important it is to be able to see the whole picture and, you know … not let it be only about the medical side, but also about the care side. Making sure to make time and, you know … so that the children will feel secure, so the whole family has to be made to feel secure somehow.’</td>
<td>‘Feel more and more that it’s important to really see the children and have time for them and see the whole family’</td>
<td>Focus attention on the child</td>
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<td>The important comforters comforting the children</td>
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<td>‘It is important to see the whole picture. It is not just the medical situation; it is also about caring for them’</td>
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<td>‘For the children to feel secure, the whole family needs to feel secure.’</td>
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the cited important comforter (IC1–IC8). The descriptions of the findings contain the ICs’ perceptions of their roles as comforters of ill children, their parents and siblings.

Caring for the whole family

The care work includes the whole family, with the ill child the focus: ‘

For the children to feel secure, the whole family needs to be secure’ (IC5).

It is important to meet the children’s needs to be surrounded by their families. Parents and siblings are close to the child. Grandparents can help with practical things and support the children and their parents.

To meet with the same staff throughout the whole treatment period facilitates comforting. One important comforter says:

‘Yeah, you get to know them and meet them at various stages; you can refer back to things, because you know the children so well’ (IC4).

Another describes:

‘You can feel it; you form a really good relationship with the children... I want to have “my children” every time’ (IC5).

Care is adjusted according to the children’s age and developmental level, and it is important to respect and listen to them:

‘Yes, you must listen to the children and ask them, and then you must pay attention to the answer, because children have much to say’ (IC6).

The ICs feel privileged to be working with ill children and their families:

‘It’s really important to remember... to establish good contact, that’s what makes the job fantastic...’ (IC8).

It is important to observe parents. Parents need to sleep, eat and take care of themselves to be able to care for and comfort their children. The ICs remind them, laugh and cry with them and provide comfort by being there.

One important comforter described:

‘The parents... deal with the most difficult thing we can face as parents’ (IC7).

Another says:

‘We’re important right here and now during this period, but we [the staff] are not the most important people in the children’s lives – that’s the family. So strengthening the families, supporting the parents – helping them cope and providing relief – that’s important’ (IC8).

Many parents manage to take care of the ill child and his or her siblings, but the ICs have noticed that siblings can be overlooked:

‘There are parents who are in despair over their ill child that they almost forget they have other children’ (IC1).

The ill child is always the focus for parents and ICs. To avoid forgetting siblings, it is essential to let the siblings come and spend time with the ill child.

The siblings need attention and want to be recognised:

‘Well, y’know, they can come and show that they’ve hurt their finger and want a plaster’ (IC2).

It is important to take time, talk with them and ask how they are. In the play therapy unit and the hospital school, siblings are doing the same things and are treated the same way as the ill children.

The children do not want to inflict pain on their parents but want to protect them. At times, the children choose another person than the parent to talk with when they want to share or have questions about the illness and treatment – things that they do not want to mention to their parents:

‘As long as you have enough time, they will tell you. It’s not always easy for the child to talk to the people they’re closest to’ (IC8).

The child can find one ‘most important comforter’ and the parent another. Children comfort parents when they are sad and cry.

They can comfort using words:

‘It’ll be ok... I can do this mummy’ (IC5), and by hugging, holding hands, being physically close, keeping their spirits up and being good and brave:

‘Children can be good at comforting in this way, by being good... by not making things more difficult for the parents, and instead keeping their feelings under control’ (IC7).

When a child is diagnosed with cancer, parents often react with sadness, frustration, anger, blame and deep existential questions about the child’s survival. Some try to accept the situation and make the best of it, while others cannot. Parents who are anxious and those who manage to stay calm and secure can convey those feelings to their children:

‘This particular mother said that as long as we [the parents] are calm, the child is calm as well’ (IC5).

They comfort their children by staying close day and night, by talking and explaining, by helping with daily routines and food, reading and playing. An important comforter says:

‘You often admire them [the parents]... They do whatever it takes just so their child can do well’ (IC5).

Parents of children with different illnesses provide one another with comfort:

‘Being in contact with others in the same situation, they find each other... The children...’
have different illnesses, but they’re all in the same situation and can support each other’ (IC5).

The parents undergo similar feelings and have the same questions. The companionship with other parents eases distress and relieves anxiety. Even when parents go home, they continue to keep in touch. At the play therapy unit parents have opportunities to talk to other parents while their children engage in different activities.

The ill children can comfort each other in different ways. They meet with other children of the same age on the ward: ‘They see other children here and are able to see that it isn’t strange to have no hair’ (IC2).

The communication can be non-verbal: ‘You see them sitting with their own infusion, looking at each other and realizing “yep, this is how it is for us”’ (IC6).

They ask one another: ‘How come you’re here and what have you been doing?’ (IC6) and they start to talk.

The play therapy unit gives the children the opportunity to talk to each other, when they are sitting down to play. When at school the children meet other children – they become acquainted with each other and therefore do not feel lonely. The children see someone else in a similar situation and find comfort.

**Important comforters comforting the children**

During initial treatment, many children are frightened, distant and withdrawn. The ICs try to become close with the children and get to know them: ‘We’re together a lot… I think it works so well when you… when the child feels safe with me, when we know and understand each other’ (IC8).

They chat about everyday matters, procedures and treatments and explain what they are doing and why. They involve the children and let them decide some part of a procedure: ‘Talking about comfort; if you can get them [the children] to not be victims, in some way feel like you can control something, then… perhaps then you can find comfort’ (IC4).

It is essential to respect the child, to have the child in the focus of care and to adjust to each child’s situation to build trust and confidence. They try to make the children feel safe with them and say the children confide in them: ‘I’ve noticed that I’m specially trusted [by the child] and get to know everything, including what’s worrying the child’ (IC2).

Comfort derives from giving children time to express suffering: ‘It feels important to give them time, to stick around and let them know that it’s okay to be sad. I’m here to help, better times lie around the corner, we’ll help them get through this time and turn it into something better’ (IC2).

The children express suffering verbally and through tears or other non-verbal communication:

‘One boy, he made mean wolves out of clay … they looked nasty, terrifying… for him it was a way to realise the horrible’ (IC4).

Spending time with the children, playing and making jokes is a central part of caring.

‘Comfort is a big thing… that there’s someone who cares and will take care of you, security from my cuddly toy or from a person … someone who can carry you when you don’t have the strength to walk’ (IC8).

When trust and confidence have developed, the important comforters can share the children’s suffering:

‘Sometimes, there isn’t a lot that you can do, I think it’s just about showing interest, showing that you’re there if the child needs you… that they feel like you care about them’ (IC1).

At the play therapy unit, the children are able to leave their illnesses behind and feel good for a while; the environment is home-like and they can meet with other children in similar situations:

‘They can feel safe during play therapy. They leave the illness behind [at the unit] and go to play therapy… it’s a “free zone” where the child decides what goes on’ (IC6).

At the play therapy unit, staff members do not remind the children of the illness and discomfort; instead they talk about other things:

‘We don’t talk about illnesses, we don’t check how often they have been to the toilet and how much they have eaten – we just talk about everything else’ (IC6).

School is an important part of a child’s life:

‘In the school we focus on healthy things, we talk about what we are going to do right here, right now – we talk about the day-to-day, not the illness’ (IC7).

The children find comfort in distraction and play and can take part in non-demanding activities they are able to manage.

**Important comforters comforting parents**

The start of treatment is the most difficult for children and parents to handle. Hearing about the diagnosis, and starting treatment, is an
extreme burden for parents. They wonder and struggle with whether their child will survive. Many parents and children can describe their worries in words, others are psychologically broken down, and not able to express how they feel: ‘The worst is when you … I think, when the child or the adults are in such a bad mental state and it’s difficult to put words to it’ (IC7). The ICs try to help parents decrease their anxiety and worry: ‘You listen to them when they have something to say or, you are just there. That’s what it feels like for me, it’s a comfort just being there, so they feel like there is someone who cares about them’ (IC1).

The treatment is tough to undergo for children that are sick: ‘Some children get so horribly sick … the first weeks are like standing at the gates of hell’ (IC4).

Parents are anxious, angry, depressed and crying. They struggle on and take one day at a time. When parents express their suffering the ICs find that being honest and telling the truth comforts parents: ‘It’s about trustworthiness. We tell them everything... We openly talk about diagnoses and prognoses, but we’re also quick to say if we suspect things’ (IC2).

Parents who are informed about their child’s illness and treatment have the opportunity to ask questions and are involved in the care of their child. These parents seem ‘secure’, and they can in turn comfort their children. It is important to be available, and ICs always try to do something to relieve suffering: ‘You can resign yourself to it as well, when it’s hopeless…. It’s easy to fall back and just stand by the foot of the bed and resignedly shake your head... but I always aim to do something, sometimes just for show, maybe just fluff up a pillow’ (IC4).

Parents feel comforted when their child’s pain can be relieved and when their child looks better than expected due to treatment. It is important to take time to sit down, talk and listen to parents’ worries: ‘Time is important, and pretending that you have a lot of time even if you don’t’ (IC5).

Difficult situations arise, for example when treatment fails or when parents are unable to restrain themselves and express worry in front of their children: ‘This is never going to work, and then you see the children shrinking… such situations are difficult, I want to slow the parents down... Of course I have to take what the parents say into account... because it’s anxiety that needs to be expressed, it’s not strange that it’s like this with all the tiredness, frustration, anxiety and fear’ (IC8).

**Important comforters feeling comforted by relating to the child**

When the ICs and child have formed a good relationship, trust and reliance are present despite painful procedures and treatments that have to be carried out. There are, for example, situations where children are forced to undergo procedures that take a long time or are painful. At such times it is difficult to accept the situation and their conscience is troubled by any pain they inflict while holding the child. The feeling conveyed by the child, that the important comforter means something special or that she or he makes a difference to the child, is comforting. One important comforter speaks of a child who preferred to use non-verbal communication: ‘He’s generally quiet. He went home and when I went into the room to tidy up, I saw “Thank you for making me better” written on the whiteboard. We couldn’t wipe it away… it warms your heart’ (IC1).

**Discussion**

During interviews held in our previous study about comfort, children with cancer spontaneously mentioned one staff member who was especially good at comforting them: an important comforter (Ångström-Brännström and Norberg 2014). A similar observation was reported by Woodgate (2006), who found that adolescents with cancer were able to identify one team member they found especially helpful in getting them through the cancer treatment. As far as we are aware, this is the first interview study with hospital staff who children with cancer have identified as being especially good at comforting.

The important comforters said they adjusted comforting measures to each child’s age, developmental stage and illness and tailored those measures to each child. The ICs also said they developed deep and long-lasting relationships with the children as a prerequisite for being able to comfort them. They saw each child as a person, met the children’s physical and psychosocial care needs and were aware of the child’s feelings and what the ongoing treatments meant to them.

The ICs gave information about procedures and treatments and let children decide some part of a procedure. Research supports that children can feel relieved and comforted when they can participate in procedures (Windich-Biermeier et al 2007, McCarthy et al 2013).
Child-centredness is an important ingredient in family-centredness (Shields 2015). By having personal relationships with the children and their families and being empathetic and sensitive to children’s, parents’ and other family members’ needs, the ICs were able to comfort the children and their families. The ICs said they did not consider themselves to be significant, and they emphasised that they did not take the parents’ role. On the contrary, they encouraged parents by helping them to participate in caring for their children.

We understand this to be the ICs’ way of maintaining adequate distinctions between the roles of nurse and parent (Hartlage 2012). They were eager to develop mutuality with the children’s family, ‘a reciprocal interaction and sharing of feelings like togetherness and equality’ (Mårtenson and Fägerskiöld 2007). Through nurturing and vigilance, important comforters could reasonably help families to maintain the balance of their family system.

The ICs explained that the child’s family is the primary source of comfort. The whole family suffers and needs comfort when a child is ill. The ICs said they paid attention to the parents’ worries and suffering and involved them in the care. They provided comfort to parents, siblings and grandparents as well as to the children. These findings are in line with studies where relatives were included, cared for, supported and comforted (MacKay and Gregory 2011, Carvalho et al 2014). Parents who are involved in the care of their child often find it rewarding, demanding and comforting (Sulkers et al 2015).

The ICs said treatment required many procedures that cause children discomfort and pain, but as the children were informed of what was going to happen, they felt safe; this seems important as research has shown that to be able to experience comfort, it is essential to feel safe and secure (Ångström-Brännström et al 2008). It seems reasonable to say that the trusting relationship between the important comforters and the ill children was an important factor for enabling the ICs to conduct painful procedures on the children, without losing their trust and confidence, as the relationship level of communication quality marks the content level (Watzlawick et al 2011). Therefore, the children could sense the IC’s kindness and concern even during painful treatment.

The ICs said they provided comfort to children and parents by sharing accurate information about the illness and procedures and by communicating with the children on the child’s level, and that they managed to identify, listen to and share the children’s fears and discomfort as the children expressed them. These findings are in accordance with Cantrell and Matula (2009), who say that it is often simple acts that matter to the one who needs comforting. Seeing the patients as a person, talking, respecting, listening and holding their hand reduces suffering and provides comfort to the person.

The ICs spoke of how they felt privileged to work with ill children and their families. There are several accounts of positive experiences connected with working as a children’s nurse (Cox et al 2007). The reciprocal nature of the relationships with children and their families was rewarding for the ICs. The ICs also talked about problematic care situations, such as having to force a child to undergo blood sampling. In such situations it was comforting for the nurses to know they were appreciated by the children. Morgan (2009) emphasises that it is important to consider the need of paediatric staff for support. In our study, ICs reported that they received support from co-workers, but lacked professional supervision.

In studies of paediatric care, support from co-workers has been found to be valuable (Zander et al 2010). Nevertheless, professional supervision would reasonably have provided additional benefits (Brunero and Stein-Parbury 2008).

Children with cancer had singled out the ICs interviewed as being particularly good at comforting them. The children did not tell us about any special traits that made the ICs good comforters. There is research that mentions important abilities such as being empathetic and becoming sensitive to patients’ needs in different situations, such as when children are
Implications for practice

- Children with cancer can identify staff members who are good at providing comfort.
- To provide comfort, it is essential to develop good relationships with ill children.
- Comforters must include and support the whole family to strengthen the families and support parents.
- It is essential that staff working in paediatric units are aware of their important roles as comforters for ill children and their families.

Limitations
Each participant was interviewed once. Repeated interviews might have revealed a deeper understanding of comforting ill children. Our participants provided a positive image of their work with ill children; during a second interview they might have reflected on what they had said in the first interview and also discussed negative experiences. More interviewees could have increased the variation in the findings. It seems reasonable to assume that the findings can be applicable in different healthcare settings for children, as comfort is described as a basic human need (Kolcaba 2003, Reich 2012).

Conclusion
The staff working in paediatric units, who had previously been identified by children with cancer as especially good at comforting them, described using comforting measures that are well known in the literature on comfort. Staff included the whole family in the care. The most important finding is that they used these measures in deep relationships with the children and their parents. The quality of the staff’s positive relationships with the children marked all their actions.

References


Johnsson E, Roche-Fahy V, Dowling M (2009) Providing comfort and care performed comforting care for the children with cancer and their parents. The findings show that the important comforters performed comforting care for the children and their parents. Being surrounded by family members with secure and dedicated staff, the children found security, safety and comfort.


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Schmidt C, Bernski L, Koski A et al (2007) Providing comfort and care performed comforting care for the children with cancer and their parents. The findings show that the important comforters performed comforting care for the children and their parents. Being surrounded by family members with secure and dedicated staff, the children found security, safety and comfort.