How do Nurses “Think Family” and Support Parents Diagnosed with Cancer Who Have Dependent Children?

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ABSTRACT

Many barriers exist regarding access to support and information for parents with cancer who are parenting dependent children and young people. There is little known about how nurses in acute settings support parents with dependent children. Many complexity factors exist which can increase the risk of behavioral problems in children when a parent has a cancer diagnosis. A recent study presented in this editorial identifies how there is a lack of confidence and skill experienced by specialist nurses in acute oncology settings regarding the needs and well-being of children where there is a cancer diagnosis in the family. Recommendations are identified for developing practice in this area and on increasing awareness of the needs of children and young people.

Key words: Parental cancer, specialist nurses, support for children

A diagnosis of cancer places an enormous strain on the family with distress experienced by all family members. The upheaval caused by having a parent diagnosed with cancer brings psychological and social pressures for children and young people. With continuing improvements in treatment cancer is now considered a chronic illness with a need for professionals to “think family” throughout the cancer care pathway and beyond. Up to now, we do not have much research evidence for practice about the effect of a parental cancer diagnosis on dependent children coupled with a lack of evidence about how health care professionals assess and respond to the needs of patients parenting children and young people. In this editorial, the background to research relevant to patients with cancer parenting dependent children and young people is discussed. A shift in thinking and practice is called for so that we not only include the “medical” but also the “health” concerns related to prevention and support, within families with dependent children and the well-being of...
Barriers to Support

Many barriers to support for children and young people exist including wishing to protect children and young people from the diagnosis and treatment of cancer. Parents were found to protect their children from the emotional impact of their illness, and therefore, avoided discussion with the children about advanced cancer. Additional to this parent’s felt that health care practitioners avoided discussions about children and health and social care staff were found to lack confidence in approaching the issue for fear of upsetting the parent making the topic “too hot to handle” for them.

A recent study exploring the experiences and needs of oncology and palliative care staff regarding support for a parent with cancer who has dependent children found a lack of confidence in staff who were found to use distancing strategies, and therefore, there was a tendency to worry about engaging with the needs of children and staff felt their lacked knowledge and guidance in this sensitive area. The themes that emerged from two focus groups held in one acute health care trust are discussed below.

Worries about engaging with support for children

Research participants were found to be apprehensive about engaging with children either directly or indirectly through the parents and some thorough that families do not welcome nursing staff initiating support for children. One staff member reported feeling ill prepared: “Never prepared until it happens” (FG1-1), and “a daunting prospect” (FG2-3), which identifies the loaded nature of engaging with the issue of children and feeling emotional apprehension and ill prepared. Similar to other studies, nurses were found to be concerned about saying things that might upset a parent, and this was a worry for them as they did not want to add to parental distress. Working and engaging with parents who have children takes an emotional toll on staff “the emotional element that’s really hard” (FG1-3) and “it is quite draining for one person” (FG2-5). Therefore, the nurses found that engaging with parents about their children’s well-being as emotionally draining and this was another reason to avoid this sensitive area.

Lack of knowledge and guidance

Many of the nurses described lacking knowledge about how to help a parent with cancer who has dependent children.

And I suppose (we need) guidance about how much to tell the children, what to tell them depending on their age and things because I suppose half the time we are blagging it are not we. What we think that we should tell them and you know (FG1-5).

The nurse above feels unprepared to confront the issues surrounding children such as how much to tell and age appropriate information. Again, this nurse feels unprepared to help parents, and her approach comes from a lack of knowledge about this area of care, and she has not got any tools to draw on in her practice.
The nurses also identified that there is more support for someone who has a terminal diagnosis where in this situation they can refer to the hospice: “I find like the hospice really helpful” (FG2-1) rather than supporting someone who is newly diagnosed they describe it much harder to get support for this group. The nurses seemed to “sit on the fence” or use “avoidance of the issues as discussed next”.

"Sitting on the fence" and avoidance
Nurses feel uncomfortable about imposing on to families’ values that may not be shared. Although they identify that there should not be a “one size fits all” approach and a consideration of “what is best” for families depending on the family culture’ (FG2-3). Other nurses talked about not wanting to impose on the family and to “enforce things on people” (FG2-5).

Another participant describes various scenarios about how families might behave regarding communication practices; however, these are very much generalizations, and overall, the nurse describes a reluctance for further discussion with the parent about children and young people.

So that is how we have to look at the patients in front of us and go with what they think (is) the best for their children. Again, I would not say I will get involved and say “oh I will come and talk to your child,” no I think it is totally left to the parents, they have the full understanding into their child’s capacity (FG2-1).

The participant above feels strongly through her words of “totally left” to the parents. These words negate any role in supporting the parent of children and young people as she feels that this is up to the parents alone who understand their situation. However, this is out of step with what patients are asking for in research previously discussed. The data suggest that nurses find the issue of children as “too hot to handle” and justify why they avoid having to connect with patients about their children.

Summary
The findings of the study identify how staff are reluctant to engage with issues of children; underlying this reluctance and avoidance is a lack of knowledge and guidance as well as support to be able to help and support parents regarding their children’s well-being. Health Care Practitioners have a role in offering support by exploring intentions and thoughts at diagnosis regarding communication with children and also exploring further down the line children’s reaction to diagnosis.[10]

Following the focus group study a workshop was convened to provide feedback on the findings and to give and receive peer support regarding the issues arising from the research. All staffs were invited to attend the workshop, which was facilitated by the two researchers and a specialist from the charity offering specialist support to children. As part of the workshop, three scenarios (case studies) were presented to staff for discussion reflecting differing levels of complexity. The feedback from the workshop was that nursing staff found it helpful to discuss issues with their peer group and to have the time to reflect on the case studies and for discussion. Healthcare professionals work in highly charged emotionally loaded situations full of sensitivities and the situation regarding children was complicated by nurses often identifying with their patients as they were of a similar age to their parents and often had children of a similar age, which made the situation even more daunting for them. Therefore, in these situations, good support and clinical supervision are necessary so nurses feel more comfortable and confident in offering support.

The type of avoidance or distancing behavior evident from the focus group data has been called “blocking behavior”[11] that may limit the extent to which patients can express concerns about sensitive matters regarding children and young people. Staff avoidance of the issues of children triggers hard to manage emotions in staff and in patients and calls for emotional labor, which may be difficult for hard-pressed staff, who feel inadequately prepared. Much research points to the needs of mothers in particular for support at all stages of the cancer illness regarding their worry about their children and the need for psychosocial support regarding these worries.[8] Less evidence is available in relation to fathers and this requires further investigation as to how health and social care professionals work with fathers as well as mothers. Working with the uncertainties associated with cancer and the chronic nature of some cancers means that patients’ needs will be variable over time and staff will need the skills to respond to these needs over longer and shorter timescales. Taking a preventative approach to the needs of children and young people is important to ensure the support and well-being of children throughout the cancer pathway and beyond. Nurses have an important part to play in offering support and access to resources throughout the cancer pathway, but especially when vulnerability factors exist.

Recommendations for practice
• Short workshops and training to increase nurses’ awareness of the impact on children of parental cancer throughout the cancer illness and to increase confidence in providing support.
• Staff needs to be aware of the risk factors that increase vulnerability factors for children and to be
knowledgeable about further referral pathways.
• Familiarity with children’s developmental stages and age adapted information and resources to help patients to communicate with their children and receive adequate support.
• Staff needs regular opportunities to reflect on practice with colleagues where they can share experiences and offer and receive peer support.

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