When Palliative Care Is a Family Affair: Serious Disease in Adults With Young Children

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The Kids Don't Know, and Don't Want to Know

Joseph is a 48-year-old immigrant from Poland who has been employed as an accountant assistant in a family business in New York since arriving in the United States 10 years ago. He and his wife, Irene, have two children, ages 6 and 13 years.

Joseph was recently diagnosed with advanced colon cancer and is now starting third-line chemotherapy and considering a clinical trial. The oncology nurse, Jim, who has been very close to Joseph and Irene, is becoming increasingly concerned about Joseph's worsening symptoms and what seems to be avoidance of any discussions of his prognosis.

During today's visit, Jim asks Joseph and Irene how the children are doing. They inform Jim that they haven't really told their 6-year-old daughter about the illness or treatment because she is too young. They say that their 13-year-old son "doesn't want to know anything" and prefers to stay with his friends as much as possible and has become very involved in school activities. Joseph adds, "Hopefully, this clinical trial will be the cure, and all this disruption will be over and our family can be whole again."

How should the nurse respond?

Your Peers Chose:  

- The nurse should fully support the patient in his hope for a cure  
  2%

- The nurse should insist that the children be seen by the child life specialist, because it's harmful for them not to get help  
  1%

- The nurse should gently but honestly tell the patient that he probably won't respond to the treatment in the clinical trial  
  2%

- The nurse should consider a palliative care consult to help the entire family  
  95%

Palliative Care: A Family Affair

This patient and his family could benefit from the support of palliative care. The nurse needs to respect the patient's values, culture, and decisions, and avoid the instinct to "fix" the situation. It would not be correct for the nurse to share prognostic information at this time. Discussing treatment options and prognosis should be a coordinated effort by the physician and team and will require time for planning and support.

Many chronic and serious illnesses are diagnosed in middle age, when it is common for patients to still have young children in the home. Many couples are having children later in life, and child-rearing can correspond with the onset of serious illness. In 2010, it was estimated that 1.58 million cancer survivors in the United States resided with their minor children (2.85 million children), and an estimated 562,000 minor children were living with a parent in the early phases of cancer treatment and recovery.[1]

Support of patients and families is a complex process that is influenced by such factors as culture, family roles and relationships, and family communication. Attention has been given in recent years to supporting children whose parents are seriously ill.
Educational materials have been designed especially for children, and counseling is often provided by psychologists, social workers, and child life specialists.[2]

Palliative care can provide support for these families. In the case above, Joseph may experience worsening disease and death. Palliative care can offer physical, psychological, social, and spiritual support at a time when having young children can create intense emotional needs. Early referral to palliative care will also allow the team to develop a relationship with the patient, spouse, and children and understand their unique needs.[3,4]

References


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