Chapter 1 : Parent feedback

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Open in a separate window Using population-based weights for the adult sample, we calculate that approximately 1. To estimate the number of minor children living with a parent with a history of cancer, we multiplied the mean number of children per cancer survivor 1. We estimate that 2. We estimate that approximately , recently diagnosed US cancer survivors were residing with their minor children. Multiplying the mean number of children per recently diagnosed cancer survivor 1. Demographic characteristics and cancer sites were very similar to the general survivor population data not shown. Discussion This paper represents the first published US population-based estimate of the proportion of cancer survivors residing with minor children. The proportion of recently-diagnosed survivors living with minor children was even larger. Our estimates are best interpreted as the population of survivors and recently-diagnosed survivors residing with minor children at the center of our time interval i. Although the overall survivor population is expected to grow in the coming years, it is not known whether this specific sub-population of survivors will grow as well. On average, the cancer survivors were almost eight years post-diagnosis. This suggests that many of them likely had young children at the time of their initial diagnosis and treatment, or in some cases, had children subsequent to their diagnosis. This is likely a particularly stressful time for young families. Additionally, the presence of young children in the household may contribute to the strain experienced by family cancer caregivers. Prior work 10 documents that cancer caregivers with dual roles caring for cancer patients and children report high levels of caregiving strain and greater emotional distress compared to caregivers not caring for children. There are several limitations to this work. We could not identify children who were not residing with their parent who was diagnosed with cancer because the NHIS only asks about people who reside in the same household. Applying this percentage to the population of cancer survivors is inappropriate because it would assume that patterns of childbearing and household makeup are similar in adults with and without a history of cancer and would not account for the demographic differences between cancer survivors and the general adult population. Similarly, this analysis focused on parents biological, adoptive, step, or foster with cancer. We did not include children residing with other relatives e. Although this number may be substantial, the psychosocial needs and family adjustment issues may be different. We also did not have information about stage, recurrence, or current treatment to know what phase of survivorship parents with cancer were currently experiencing. Specific needs of minor children during different phases of the survivorship experience need to be assessed in future studies since the impact of a cancer diagnosis is likely different not only by the age of the child affected, but also based on whether or not a parent is expected to survive for an extended period of time i. In this analysis the data on cancer diagnosis type and timing were self-reported: Finally, this sample is representative of United States adults residing in the community, and thus best reflects the population of long-term survivors. However, cancer survivors in the NHIS may not reflect patterns of cancer incidence, and cancers with shorter survival are under-represented. According to National Cancer Institute Surveillance, Epidemiology, and End Results SEER statistics, the most common cancers diagnosed in individuals aged 20â€"40 include Hodgkin lymphoma, testicular, melanoma, thyroid, breast, and cervical cancers 1. These sites were all among the most common cancers diagnosed among our sample of survivors living with minor children, with the addition of uterine and ovarian cancers. Brain and other nervous system cancers are also among the most common cancers for young people between the ages of 20 and 24 1 , but were not among the common cancer sites in our sample, possibly because of relatively lower survival rates. The majority of the identified cancer survivors living with their minor children were female. Females between the ages of 20 and 45 years of age are more likely than males to be diagnosed with invasive cancer, but they are also less likely to die of cancer after diagnosis In addition, women are more likely to be single parents or reside with their children after divorce, This suggests that females should predominate among the group of long-term survivors living with their minor children. Unfortunately SEER does not collect data on

family structure and thus, reliable population estimates for the number of children who have lost a parent to cancer are not known. A rough estimate can be obtained by applying the percentage of newly diagnosed survivors residing with minor children from the NHIS to SEER estimates of the number of cancer deaths that occurred in persons 20â€"64 years of age 89, cancer deaths in men and 81, deaths in women for This would result in an estimate of approximately 29, deaths estimated to occur among cancer survivors with minor children. Futher, multiplying this number by the mean number of children per survivor from the NHIS results in an estimate that approximately 55, US minor children had a parent who died of cancer. This is a rough estimate at best because it assumes that the pattern of childbearing is identical between recently diagnosed adults with cancer and those adults who die of cancer. It is likely that the adults with a history of cancer who respond to the NHIS are healthier over their lifespan than adults who die of cancer and thus may have more children. Further, the estimate does not fully account for differences in the likelihood of having children at different age ranges. Our analysis of the NHIS indicates that more than a million US families with minor children are faced with cancer in a parent. We hope that by documenting the significant number of families affected, greater attention will be given to the identification of these potentially at-risk groups. Further, it is hoped that increased awareness of these figures will lead to future studies that expand our understanding of the public health impact of cancer and guide appropriate psychosocial service planning. To facilitate these goals, future studies should identify the characteristics of those families that place them at greatest risk of poor adjustmentas well as the characteristics of those families who are doing relatively well after the parent has cancer, and also identify the comprehensive needs of all members of these families. For example, the needs of families with teen-aged children are likely to be different from the needs of families with very young children. Needs also may differ depending on the extent and nature of the long-term and late effects of cancer the parent is experiencing, or by family structure or type of family dynamics. Future research should also test tailored interventions that meet these needs to determine what works, for whom, and when in the course of survivorship it should be delivered. Finally, routine assessment of family adaptation as well as referral to appropriate support services has been identified as a key component of survivorship care. Some promising interventions to help these families are currently in development. However, to ensure integrated, comprehensive care for these families in the future, examination is critically needed of clinical delivery systems that allow for the efficient and effective screening, referral, and follow-up of these families, and that work within, and where possible leverage, extant healthcare structure, reimbursement, and staffing constraints. Acknowledgments The authors gratefully acknowledge Dr. Diana Jeffery and Dr. Noreen Aziz for their helpful feedback during the inception and shaping of this manuscript. Footnotes There are no financial disclosures for any authors. National Cancer Institute; Long-term effects of cancer on families of adult cancer survivors. Handbook of Cancer Control and Behavioral Science. American Psychological Association Press; The impact of parental cancer on children and the family: The psychosocial impact of parental cancer on children and adolescents: The impact of parental cancer on the adolescent: Adjustment of children and adolescents to parental cancer. Cancer care for the whole patient: Meeting psychsocial health needs. National Academies Press; National Center for Health Statistics. Questionnaires, Datasets, and Related Documentation â€" Psychological adjustment of cancer caregivers with multiple roles. Urban Institute, and Child Trends. Westate [producer]; Ann Arbor, MI: Inter-university Consortium for Political and Social Research [distributor]; Cancer prevalence and survivorship issues: J Natl Cancer Inst.

Chapter 2 : Patient/Family Feedback Form (PFFF)

Patient and family feedback gathered through interviews on pediatric inpatient unit and in outpatient clinic setting Parents evaluated a laminated color copy of the revised AAP to be built electronically for.

Spiritual considerations Spiritual considerations are one of the content items of communication between the families and ICU team. As the patients in this department are in critical condition, premonition of the diseases is not satisfactory and all people consider the spiritual issues more than any time and ask God to get the patient better and they consider their religious actions including worship, praying or fasting and by praying to Allah get help for their patient. It is observed that the nurses asked the families to say prayer for their patients and ask for help. Giving hope If there is no hope for getting better, again the families of the patients try to be given hope from the ICU team. Even they feel they are telling lie. One of the nurses said: Considering God The nurses guide the families to God and saying prayer when they thinking that there is no hope to relieve them and they can tolerate the sad moments. It can be said that they establish spiritual relation with the family. Resorting to religious actions Religious beliefs are more important at disease time than other periods in life and it is caused that a person accepts the disease. Thus, religious actions and providing required facilities for religious actions and meeting the religious demands of the patients when the patient is hospitalized in the hospital are of great importance. In all the observations conducted by the researcher, resorting to religious actions was observed. As some of the families were saying prayer, some others were sending peace upon the Prophet and reading the Holy Quran. The major concern of the patients to treatment costs, dismiss and outcome of the disease were the major cause of anxiety. One of the ICU nurses said: They say, our patient will get better, are all the treatments for our patients good and effective? Empathy Empathy with the families and giving them comfort is one of the important issues being mentioned by the families. They wanted the ICU team to empathy with them. One of the participants said: Mutual understanding The families preferred the nurses and physicians understand them and in this way most of communication problems are resolved. The sister of one of the patients said: The father of one of the patients said: Comfort Giving comfort to the family of the patient is one of the communication behaviors of the nurse in facing with the critical needs of the patient and family. The nurse by some behaviors as being friendly and respecting the patient and empathy with the needs of the patient said that not to feel themselves as a stranger and it was a comfort for him. One of the families said: Giving comfort to the patient is one of the actions. One of the nurses in ICU said: Most of the families said that giving comfort by the ICU team reduced the stress and anxiety. A sister of a patient said: I trusted them and I relieved. The brother of one of the patients said: They were giving us information. They said, our patient is getting better and it was understandable. Trust Communication with the families causes that they trust you. Participation Other content of communication in the present study is participation. Based on the two features of audience as participation and participation content. Participation in decision making In ICU, due to the critical condition of the patients and immediate decision making for them is asked less than the families. In most cases, they are informed and the consent is obtained. If the necessary measurement is taken for the patient, the families are asked to take decision about their patient, for example, transferring other hospital and so on. Participation in physical care Rarely, it is happened that the families are asked for help in ICU. ICU is an isolated location and frequent visits make this place infectious but in post-ICU, the families are asked for physical care. The identification of the information need of the families Another type of communication content is giving information to the families and obtaining information about the patient from the families. The major content of communication is done via exchanging information. Obtaining information about the patient is one of the important needs of the families and the families are more anxious about their disease and premonition and they need to have the complete information and if the needs are not met, they feel anxious. Based on the conditions in the study field, the nurses had time to focus only on critical issues related to patient health and the content of their communication was responding the needs. What are we doing in this process and sometimes the families want to know completely about the disease. Responding the information need of the patient families Responding the family need to the health of their disease was due to the concepts

leading into the needs of the families. This concept showed the role of patient family in this group. Most of the families tried to obtain information about the disease, diagnosis, treatment and their disease. For example, a nurse said: Increasing the information of the patient or his family is in the form of explanation with the disease process, patient preparation to implement care techniques and care recommendations to the patient or the family. Consultation in selecting the therapy One of the groups of communication content is consultation of therapy team to the family to select the best therapy. The families require ICU team consultation for better choice. In most cases, the families are guided by the therapy team to have the best therapy services for their patients. We do our best that our patient feels better. Consultation in selection the best type of care The brother of one of the patients said: When the patients were dismissed and they needed nursing care at home, most of the families were searching for a center or a person for nursing his patient at home. A family asked the nurses: Misunderstandings about treatment needs B. In one instance a nurse stated: Perceptions of unfair treatment A conflict occurs when the patient has the perception of unfair treatment by the nurse. Perceptions of unfairness have featured prominently in this study. In some cases the nurses reported that they provided priority services to patients with more serious conditions and were upset by those who had less serious conditions and wanted prompt care. Using their professional judgment, the number of nurses reported that they thought critically ill clients were more in need of urgent attention. A nurse quoted her patient family as saying: Nurses complained that visitation by family members outside the stipulated visiting hours disrupted their work, disturbed other patients and threatened their privacy. Failure by family members to observe visiting hours elicited negative responses from the nurses. We told them to leave as we were in the process of ward rounds but they refused to leave the ward. Miscommunication Negative interactions between nurses and patients family occurred when information given by nurses was not properly understood. Patients misunderstood what the nurses said and this resulted in adverse health outcomes. For example, the nurses reported that a patient did not receive the right information from the nurse about his treatment needs. Nurses were perceived as powerful and patients as powerless. This unequal relationship was seen as a barrier to effective nurse-family interactions. Forced dependence Forced dependence is defined as the use of force by a nurse to condition the patient. In situations where nurses have perceived patients to be difficult, the nurses applied forced dependence measures to compel their clients to obey orders. Staffing shortages were such that nurses did not have adequate time for their patients. Few numbers of nurses coupled with high workloads led to inadequate interactions with patients. Nurses attributed the nursing shortage to the migration of nurses to other countries such as the United Kingdom and the United States. Reflecting on the nursing shortage, one nurse participant stated: That is happening and during the night, a nurse will attend to about 30 children with one ward. You can well imagine the workload and the frustration that happens under such circumstances. Professional nursing problems Task orientation and organization made it difficult for nurses to give holistic care to their patients. All nurses mentioned that they had to combine tasks in order to complete them which dissatisfied their efforts to render holistic care to patients. The nurses were busy and unable to communicate effectively with their patients. Nurses have become so adapted to this situation that they forget to teach and communicate with patients even when they are less busy. Nurse Problems Nurses who stay in rented premises outside the hospital cannot effectively respond to emergency calls. Stress, tiredness, frustration and long working hours without a break affect nursing attitudes, which has serious negative implications for patients and their family members. The nurses noted that stress and overwork led to frustration and anger in the work place. In some cases, nurses identified personal issues as justification for how they interacted with patients and their families. According to one nurse: Negligence by nurses or failure to take proper care of patients by nurses has emerged strongly in this research which was acknowledged by all participants. As one nurse stated: Lack of concern about staff by managers interfered with nurse-family member communication. Many nurses who left the hospital sought employment elsewhere in Kerman. Difficulties with patients B. In some instances patients refused to be admitted even when it was strongly advised. Such professional advice was resisted by the patients because of financial reasons. One nurse quoted her patient as saying: Of nurses, mentioned that patients found fault with everything the nurses did for them. According to Irurita 20 , an effective nurse- family relationship was considered to be central to quality nursing and emotional support.

Chapter 3 : Parent feedback form

We want your feedback! Please take a minute to fill out this short survey.. At UPMC Children's Hospital of Pittsburgh, we're creating a family advisory board, which will allow us to get helpful feedback from patients and families on their visits and ensure improved visits for families in the future.

After all, the focus is on healing the patient. But up close, the view is very different, as anyone who has ever received or delivered care knows. Patients and family members feel that their questions, concerns or preferences are ignored or never sought, and committed caregivers feel overworked and under-appreciated. Worse, a growing body of research suggests that the lack of productive communication between patients and caregivers contributes to ineffective or inappropriate care, or even fatal errors. To address these issues, in the Institute of Medicine IOM established patient-centered care as one of its six aims for the health care system. In Crossing the Quality Chasm: Pediatric hospitals have been ahead of the curve on some aspects of family-centered care, for instance, having long ago provided accommodations for parents to sleep next to their children. Sorrel King knows this too well. Patients and Families Are Leading the Way Learning to work with patients and families as true partners in their own care is neither easy nor intuitive. It involves significant changes, both cultural and logistical. But pressure to do so is increasing. But pressure from patients and family members such as Sorrel King makes this change inevitable, says Jim Conway. Our patients and families are taking us there. The incident received widespread media coverage, and focused the Dana-Farber as never before on finding and fixing communication gaps, and on re-establishing trust and respect among patients, families, and caregivers. Conway underscores this notion: Moving Beyond Good Intentions Changes such as these require a new way of thinking. They got lots of answers, particularly about the way physicians provide information to families. This is not just good manners. Among other tasks, these councils work with faculty members to create training programs for residents on how to talk with patients. Learning To Listen But a true partnership involves more than just giving information. Caregivers must also be willing to seek and respect input from patients and family members on issues both broad and specific. But, he says, the effort is worth it. But it is important and necessary. All inpatients are given a brochure that describes the service, and a video is in the works for patients that tells the Josie King story and why UPMC Shadyside is committed to encouraging the use of Condition H. Although there is not enough data yet to detect strong patterns or trends, Kuzminsky says that all of the calls have been carefully reviewed and found to have been appropriate. Sorrel King says the mere existence of Condition H helps to change the culture. And the benefits could be profound. Everybody Benefits Communicating effectively with patients and families means giving them easy access to relevant information. But when a pilot test went well, attitudes softened, and eventually the practice spread to all ICUs. And there is no more dressing down of residents, which was inappropriate anyway. There are fewer surprises for them. Families have been included in rounds in the ICU at Lourdes since early , and Fuchs says it has worked well, saving nurses time and making patients and families happier. All this work to improve patient-centeredness has a common foundation, says Susan Grant. It takes a belief in transparency, an ability to let go of fears of litigation, a willingness to walk the talk and be a true learning organization. As you get better at it, you experience fewer and fewer problems. Physicians who are uncomfortable with this scenario are coached on appropriate ways to ask parents to step out of the room.

Chapter 4 : Children's Hospital Family Feedback Program: Patient and Family-Centred Care | Hospital

Instructions: Please let us know how you feel about the care you and your child received. This will help us to improve our care and services. Patient and Family-Centered Care means we value, respect, and encourage the sharing of information to work with you in caring for you child.

Families as Advisors What is a family advisor? We value the unique perspectives and expertise of families. Families have much to offer, teach and share. What does a family advisor do? You can help develop family-centered healthcare practices, programs and policies. As an advisor, you could: Take part in feedback groups that focus on change. Become a member of a committee. Review written or web-based materials. Become a member of the Family Advisory Council. Issues are identified, for example, how surgeries are scheduled or how medicines are ordered at discharge. Workgroups are created to look at challenges and solve them. Parents have participated in hour-long panel discussions or week-long workshops. These orientations include an open discussion about what leads to effective partnerships with patients and families. They meet with the parent of a patient and learn about the patient and family experience. From the onset, anesthesia residents understand the importance the hospital places on partnering with families by sitting down that very first day with a parent. We use the feedback to improve the writing and content, and share it with clinicians so that we are making our materials as patient- and family-centered as possible. Could I become an advisor? You would make a good family advisor if: You like to work on a team. You are willing to reflect on your experiences. You are open to learning about yourself. You can speak up honestly and thoughtfully. You have time and interest to work on behalf of all families.

Chapter 5 : Patient & Family Survey | Children's Hospital Pittsburgh

The Patient and Family Feedback Policy exists to strengthen, personalize and enhance the relationship between patients, families/partners-in-care and the health care team. Complaints and compliments are unique opportunities for evaluating our delivery of care and.

Chapter 6 : Families as Advisors

of care, increase patient and family satisfaction, as well as provide hospital staff the tools needed to better manage patient transitions. These self-assessment surveys were piloted at a number of hospitals, rehab units in nursing homes.

Chapter 7 : Delivering Great Care: Engaging Patients and Families as Partners

Obtaining Patient Feedback There are a number of ways to obtain patient and family feedback. Obtaining feedback from patients and families often provides the practice with information and perspectives that might not be immediately evident to physicians and staff.

Chapter 8 : Patient Surveys/Questionnaires -- FPM Toolbox

If your e-mail is related to an urgent health concern please note that Patient Relations does not provide medical advice. Please phone Telehealth Ontario to speak with a registered nurse at , call your family physician or in case of an emergency call immediately and/or go to the nearest emergency room right away.

Chapter 9 : Families Providing Support

For especially complex patients or situations in which daily rounds are not sufficient to cover the patient's and family's needs, separate patient care conferences are scheduled for families with all the relevant specialists.