

Original Article

Custody Planning: A Retrospective Review of Oncology Patients Who Were Single Parents

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Abstract

With rising numbers of single-parent families, a phenomenon becoming increasingly prevalent is the child orphaned by cancer. We sought to examine issues related to custody planning addressed prior to the patient's death. Ten deceased patients with minor children were identified. The contact person was administered a brief questionnaire regarding the minor children and custody issues. The study involved twenty children, ages ranging from 3–20, mean age 9.8. Only five of the ten families developed custody plans that were ultimately successful. One-half of the families reported the patient had suffered with this issue and almost one-half of the children were not aware of the custody plans that had been arranged for them. In 40% of the cases, the children ultimately went to people to whom the deceased parents were opposed. It is our belief that if we can improve these statistics, we might improve the quality of life of these families. J Pain Symptom Manage 2001; 21:380–384. © U.S. Cancer Pain Relief Committee, 2001.

Key Words

Custody planning, permanency planning, parental death

Introduction

According to the Census Bureau, in 1996, 28% of children lived in single-parent families.¹ Approximately 1.5 million children in the U.S. live in single-parent homes because the other parent is deceased.² It has been estimated that by the year 2000, the total number of motherless children in the United States secondary to the AIDS epidemic will exceed 80,000.³ Cancer is the second leading cause of

death in the United States.⁴ With the vast number of single parents, and the incidence of cancer on the rise, a phenomenon becoming increasingly prevalent is that of the child orphaned by cancer. There has been much research about HIV and its effects on children, but there is a lack of literature regarding custody planning specifically for cancer patients. In fact, much of the information reviewed in preparation for this project focused on HIV patients and their families.

A parent's life-threatening illness presents uncertainty and anxiety for children and the family unit as a whole. Researchers involved in this project were becoming increasingly aware of single parents who were diagnosed with cancer and were the sole caretakers of their children. In some cases, the patient was married,

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but to a nonbiological parent of the child, and custody plans had not been made. Some of the parents had strong opinions about whom they did *not* want their child/ren to live with, but had not made any legal arrangements. For parents who face terminal illness and eventual death, one of the most painful aspects of their disease is the realization of their inability to care for their children, plan their futures, and see them grow to maturity. For both patients and health care providers, there is often a degree of wishful thinking about custody options for the children involved. In truth, a perfect plan seldom exists and most arrangements are vulnerable.⁵ We speculated that if some of these issues could be resolved prior to the patient's death, then perhaps the quality of life for the patient and the family might be improved. We were interested in determining if there was a need for intervention in this area of terminal care at our institution.

Each year, six out of ten Americans die without a will. Investigators have found that more than half of the parents with AIDS die without having made a formal plan for the long-term care of their children. Far fewer of those plans have actually been formalized legally.⁶ The custody plans of parents living with AIDS vary according to their children's age. Half as many families make custody plans for older children as for younger children.⁷ Similarly, studies of elderly parents of adult children with disabilities indicate that most deal with custody plans by not deciding.^{8,9} Substitute care is difficult to discuss and the topic is therefore avoided.

The purposes of this research project were: to retrospectively identify single parents who had died, leaving minor children; to examine issues related to custody planning addressed prior to the patients' death; and to obtain an assessment of the children's well-being from the contact persons. Also of interest were the patients' experiences with the planning and their degree of distress about the issue. There was a goal of determining whether a concerted effort towards assisting patients with custody planning would be warranted.

Method

This study was approved by the Health Sciences Institutional Review Board (IRB) of the University of Missouri-Columbia. Ten de-

ceased patients with minor children were retrospectively identified as being either a single parent or married to a non-biological parent. All subjects had died within the past year. The researchers developed a questionnaire with eleven questions (Table 1). It was decided to keep the questions brief, in an effort to avoid intrusiveness. The questions were designed to obtain only information felt necessary to address the study goal of whether the issue of custody planning was being adequately addressed. The patients' listed preferred contact persons were contacted by telephone and the questionnaire was administered after obtaining consent to participate. Two social workers and a nurse collected data and no one contacted declined to participate. In most cases, a team member who had worked with the family during the patient's illness phoned the contact person. This was decided to be optimal for the surviving families, as a random call from a stranger was felt to be more intrusive. Families were contacted over a period of two months, as some were difficult to contact.

Results

This study involved ten patients and twenty children (18 minor children) with ages ranging from 3–20 years. The mean age of the children was 9.8 years, and the mode and median age were both 9. In seven cases, custody plans were made (some verbally, some formally) prior to the patient's death, but two of these plans fell through, leaving only 5 of 10 successful custody plans. Seven of the ten families re-

Table 1
Custody Planning Questionnaire

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1. Age and sex of dependent?
 2. Who is dependent living with now?
 3. What is their relationship?
 4. Were custody plans made prior to the patient's death?
 5. How were custody plans arranged?
 6. Did the patient suffer with this issue?
 7. Was this discussed during the patient's treatment?
 8. Did the dependent know about the plan before the patient died?
 9. Have custody plans been legalized?
 10. Were there problems concerning custody following the patient's death?
 11. What could we have done to help the patient with the custody issue?
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ported the issue of custody planning had been discussed with the patient during treatment. When the attending physicians were queried regarding the remaining three cases, they reported talking with two of the three patients about the issue during treatment. Five of ten families reported that the patient had suffered with the issue of custody planning, and nine of twenty children involved had no knowledge of who would care for them, should their parent die. One patient, a mother of three children, had outlined a plan for custody in her will, but had not shared these arrangements with her children. In another case, the plan the parent had made was unacceptable to the children and created a suicidal crisis for one of the children. In 40% of the cases, the children ultimately went to people to whom the deceased parents were adamantly opposed. After approximately one year, seven of the cases now have custody arrangements legalized, two have

not, and one is uncertain of the legal status of custody arrangements (Table 2).

Discussion

As a routine practice, the physicians, nurses, and social workers in our institution address the issue of custody planning with patients and families, but are frequently met with resistance. We found that 9 of the 10 cases surveyed had had custody planning specifically addressed during treatment of their cancer, but this resulted in only five successful custody plans. Patients often avoid the topic, perhaps as part of a defense mechanism. People finding themselves diagnosed with a malignancy tend to focus on living, treatment of their cancer, and financial concerns. They don't want to think that their disease may be fatal and that they may not be able to see their children to maturity. The eventual outcome of their illness, however, is not changed by these

Table 2
Results of Custody Planning Questionnaire

Patient	Age and sex of dependent?	Who is dependent living with now?	Were custody plans made prior to the patient's death?	Did the patient suffer with custody issues?	Was this discussed during the patient's treatment?	Did the dependent(s) know about the plan before the patient died?	Have custody plans been legalized?	Were there problems concerning custody following the patient's death?
1	Female, age 7 Male, age 5	Individual biological fathers	No	No	Yes	No	Yes	Yes ^a
2	Twin females, age 6	Uncle	Yes	Yes	Yes	Yes	Yes	Yes ^b
3	Female, age 12 Female, age 9	Father	Yes	No	No	Yes	Yes	No
4	Female, age 13 Female, age 9	Grandparents	No	Yes	Yes	No	Yes	No
5	Female, age 13	Grandparents	Yes	No	Yes	Yes	Yes	No
6	Female, age 18 Female, age 17 Male, age 14	Grandparents, sister	Yes	Yes	Yes	Yes	Yes	No
7	Female, age 4	Grandparents	Yes, but fell through	No	Yes	Yes	Yes	Yes ^c
8	Female, age 9 Female, age 8 Female, age 4	Individual biological fathers	Yes	No	No	No	Yes	No
9	Female, age 20 Female, age 10 Male, age 9	Biological father	No	Yes	Yes	No	Yes	Yes ^d
10	Female, age 3	Relatives	Yes, but fell through	Yes	Yes	No	Uncertain	Yes ^e

^aSuicidal crisis on part of the 7-year-old female, requiring DFS involvement to resolve placement issues. Child now in custody of biological father whom she had never met.

^bCustody plan required multiple court appearances to legalize.

^cChild was initially placed in non-biological adoptive home chosen by deceased parent, followed by custody battle with maternal grandmother who now has custody.

^dCustody battle between biological father and stepfather.

^eChild initially placed with close neighbor, relatives unknown to the child arrived at funeral and assumed custody of the child.

avoidance patterns. Many of the patients, as demonstrated in our study (50%), die without established custody plans for their children.

Almost one-half of the children involved in our study were not informed of the custody plans that had been arranged for them. Our limited survey did not address the issue of whether the children were informed of the diagnosis, or the impending death of the parent. Our findings document a great deal of stress on the part of these children. The course of cancer is often protracted, and, even when children are not told that their parent's condition is unresponsive to treatment, irreversible, or terminal, clinical experience suggests that children are generally aware of the severity of illness and the parent's progressive deterioration and increased disability.¹⁰ We believe that increased communication with these children will improve the quality of life of the entire family.

The sample size for this project was small, partially due to the fact that data are not kept on this specific population. As a result, we were forced to depend on the recollection of health care providers of patients who had died in the previous year leaving minor children. Because we do not follow every patient after treatment ends, it is difficult to determine exactly how often custody planning is an unmet need. Our study shows that it is a significant problem, causing distress to our terminally ill patients. We are in the process of developing a bereavement group which will likely increase follow-up with patients' families. With increased follow-up, we may find that this issue is even more prevalent than currently recognized.

The fact that no data are collected on children orphaned by cancer leads one to wonder how many children are affected. A search of the National Cancer Institute, the American Cancer Society, Census Bureau, Department of Health, Division of Family Services, and Cancer Registry turned up no data regarding this issue. With cancer being the second leading cause of death in the United States, this would be beneficial information. More research about children orphaned by cancer is needed.

In addition, there is a lack of knowledge on the healthcare providers' part regarding what to do for patients and families facing the issue of custody planning. In the process of administering the questionnaires, families had several

suggestions for improvement. These included making the children more active in the process, and giving the children more information regarding the custody plans. The families suggested the hospital provide more age-appropriate literature and make available individual and group counseling to the children. It was also suggested that hospital staff be more frank with patients when discussing prognosis and the need to make arrangements for the children. We plan to institute many of these suggestions in our future interactions with patients and their families.

Our group is planning a second phase of this project. The objectives of this phase will be to increase awareness of the need for cancer patients to make custody arrangements for their children in the event of the patient's death and to make the resources available for them to do so. The project group is in the process of developing several interventions, including education, counseling, and legal services. The focus will be single parents, or parents married to a non-biological parent, who have made no legal custody plans for their children. A counseling session will be provided with the goal of determining a need and desire for assistance with arrangements. Legal counsel will be provided if needed. Educational materials, made available to all patients, will include videos, booklets, and workbooks regarding custody planning. The group is in the process of educating staff about this new service and gathering educational materials. It is hoped that through these interventions, we will be able to increase the success rate of custody plans and provide an improved quality of life to our patients and their families.

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