Published in final edited form as:

J Hosp Palliat Nurs. 2016 August ; 18(4): 302–309.

An Examination of Interactions between Hospice Health Care Providers and Adolescents with a Parent in Hospice

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Abstract

Interviews conducted with adolescents living with a dying parent were examined to identify the type of interactions the adolescents had with members of a hospice healthcare team. Four types of interactions were identified: No Interactions, In-passing Interactions, Engaged Interactions, and Formal Interactions. Results indicated that most of the adolescents had no contact with the hospice healthcare team or interacted with providers only briefly. Some adolescents reported more engagement with one or more hospice healthcare team members, and a few received formal counseling services from the hospice healthcare team or outside provider. Overall, limited contact occurred because of logistics or because the teens perceived that hospice services were exclusively targeted to dying patients, not their families. Based on these findings, strategies to increase engagement between adolescents and hospice healthcare team are discussed.

Introduction

The National Hospice and Palliative Care Organization estimated that approximately 240,000 adults between the ages of 35 and 64 - prime ages for parenting adolescents - received hospice care in 2012. This suggests that many adolescents in the United States experience not only the death of a parent but also the stress of living in a household with a parent who is seriously ill or dying.¹

Adolescence is a time of physical changes as well as meaningful social / psychological growth. Teens face the tasks of establishing a separate identity from their parents, developing close friendships and in the later phase of adolescence more intimate relationships.^{2, 3, 4} The death of a parent in childhood and adolescence can result in psychological and social difficulties^{4, 5, 6} that may persist and extend into adulthood.^{7, 8} Ongoing struggles with depression, self-injury⁹ and posttraumatic stress symptoms¹⁰ are common. Less is known about the effects of the traumatic stress due to exposure to living with a dying parent, perhaps due to the belief that children are generally adaptable. Some studies, however, indicate that how children and adolescents fare during this time depends upon their age, which parent was ill^{11, 12, 13} and how the children cope. For example, adolescents' reports of anxiety and/or depression vary according to the degree that they

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Author Disclosure Statement: The authors of this report have no competing fiscal interests.

utilized active¹⁴ versus avoidant (e.g., substance use and behavioral disengagement) coping strategies¹⁵ around the time of their parent's death.

Several studies have provided an in-depth description of what it is like for teens to live with a dying parent. Buchwald,¹⁶ for example, found that adolescents depict living in the household with a dying parent as being in “death's waiting room” where impending loss and grief are inescapable. In another study, adolescents reported the experience of a “life interrupted” because they faced uncertainty, fear, and a loss of control² as they struggled to provide what care and comfort they could to their parents as their health declined. Sheehan¹⁷ noted that main concern of teens when a parent was dying was that they – the adolescent and parent – did not have “enough time together.”

Adolescents whose parents are dying may need support from healthcare providers to cope with the challenges the adolescents' experience. Nurses operating within a family-centered framework are well positioned to extend this assistance. One of the guiding principles of hospice, for example, is that the unit of care includes both the patient and family.¹⁸ Yet some research suggests that nurses may experience obstacles in providing help for children of dying persons. The nurses may see their role as caring for the ill parent only or may be uncomfortable or inexperienced talking to children and adolescents about sensitive topics such as death and grief.¹⁶ Parents may also discourage or restrict interactions between their healthcare providers and their children if the parents have withheld information about their illness from their children. Additionally, children and adolescents may obstruct communication. They might withhold expressing their fears or concerns in order to not worry their parents¹⁹ or they may hide their feelings so they do not appear different or because they lack the skills to express themselves.² If the healthcare team does not address the needs of children and adolescents of dying parents, they may not only be deprived of information about a parent's illness and course of treatment but may not get the psycho/social support they need to deal with the stress and grief they experience.

Little is known about interactions between adolescents with a parent who is dying and the hospice healthcare team (HHT). There are only a few small studies which address communication and the healthcare team. These studies suggest that adolescents want information but either did not perceive they had access or that they were the focus of care.^{16,19, 20,21} One study stated that there were no reports of teens talking with the healthcare providers.¹⁶ There were mixed reports as to whether adolescents wanted to talk with the providers, but teens did state they did not feel they had their informational and support needs met²¹.

More information is necessary to develop strategies that can be used by HHT to provide support and guidance for adolescents living with a dying parent. The purpose of this study was to provide a description of the variety of ways in which adolescents and HHT interact during the time a parent is close to death. This study is part of a larger project titled Strategies to Help Adolescents with a Parent in Hospice (referred to as “Adolescents Strategies Study”), the aim of which is to investigate the strategies adolescents use to cope with living with a dying parent.

Adolescent Strategies Study

The Institutional Review Board of at Kent State University approved the study protocol and all related activities. Families receiving services from a large hospice located in the Midwest were recruited to participate in the study. To be eligible, the family had to have one or more teen between the ages of 12-18, and the dying parent or primary caretaker (e.g., grandparent if parents not living/available) had to have sufficient stamina and cognitive ability to complete the interview process. All participants had to be fluent in (spoken) English.

Participants were referred by the HHT. To facilitate this process, a member of the research team attended the interdisciplinary hospice team meetings to present an overview of the study and criteria for participation and to answer any questions or concerns the hospice HHT might have. Over the course of data collection, updates were shared at these team meetings. A designated research associate contacted and screened families referred by hospice staff to ensure the family met eligibility criteria and scheduled appointments with the parents/ caretakers and adolescents. Enrollment data presented in Figure 1 show the number of families identified by hospice staff who met eligibility criteria (45), and the 26 families who elected to participate. Eleven of the 19 families that declined to participate did not offer a reason.

A total of 30 adolescents (18 daughters and 12 sons) from 25 families provided data for the present study. (One adolescent in one family declined participation when her mother suddenly declined on the day scheduled for the interview.) A second interview after the death of the ill parent was conducted with six families (six surviving parents/grandparents and nine adolescents. The data from the nine adolescents is included in this analysis.

Participants were interviewed either in their homes or private rooms of the in-patient hospice facility. After written consent was obtained, individual interviews and field notes were digitally recorded transcribed and managed utilizing NVivo9 software.²² To ensure accuracy and data integrity, transcripts were reviewed by the interviewer. Interviews, which averaged 45 minutes in length, were conducted by a member of the research team with experience in palliative and hospice nursing. Data was collected between December 2010 and July 2012. A \$35 honorarium was given to each family member who participated in the study. All participants were told that the interviews were confidential unless the adolescents reported thoughts of harming herself/himself or another person and that the participants could stop the interview at any time.

The interview consisted of a series of open-ended questions about the trajectory of the parents' illness and the adolescents' experiences while their parents were dying. Constant comparison analysis²³ was used to develop two theoretical frameworks that have been previously described. The first illustrates how parents told the adolescents that the parent was dying in different ways but all with the intent of making it "easier to swallow".²⁴ The second framework explains how adolescents navigated between the "ill world" and the "well world" in the final months of their parents' illness.²⁵ Sometimes the teens tried to keep these worlds separate but as the illness progressed, the adolescents became more "immersed in the

ill world". This study addresses the descriptions of the how the adolescents interacted with the HHT that were embedded in the narratives.

Data Analysis

For the purpose of the present study, standard content analysis procedures were used with the adolescents' narratives from the larger study.²⁶ All text units related to interactions the adolescents had with HHT were highlighted, extracted, and coded. The interactions were discussed by the research team and, by consensus the team divided the text units into the four categories described below. Because the categories were straightforward and involved a low level of interpretation, all team members readily agreed on what type of interaction each teen described. Information provided in the parents' narratives about interactions between the adolescents and the HHT were used to substantiate the adolescent narratives. Common features of each type of interaction were identified.

Family and adolescent demographics are reported in Table 1.

Results

A review of the 30 transcripts identified four types of interactions between the adolescents and the HHT: No Interactions (n = 12), In-passing Interactions (n = 6), Engaged Interactions (n = 6), and Formal Interactions (n = 6). Each type is described below, and salient quotes from the teens about each type of interaction are included.

No Interactions

Twelve teens, eight daughters and four sons, were placed in the "No Interactions" group because they had no contact with any provider from their parents' HHT. This group was twice as large as any other group and represented the widest range of ages. The teens reported a number of reasons why they did not interact with the HHT whom provided care for their ill parents. Several teens indicated that the timing of the visits by the HHT prohibited contact. One 17-year-old son whose grandfather [and primary caretaker] was dying from cancer explained that, "The hospice workers and nurse will come when I am at school so I don't really see them," and another 16-year-old son whose father was dying of cancer stated, "I don't usually get home until like 5:30..." Some teens missed the HHT because the teens were out of the house more than usual because of additional responsibilities they had due to their parent's illness. One 17-year-old son whose mother had cancer reported, "I haven't been here [home]. I have been busy with making up school work because I am missing a lot."

Some of the adolescents did not perceive themselves as the recipient of care. One 14-year-old daughter whose father had a brain tumor stated, "...is he [HHT provider] going to sit down and talk to me, because why would he? His [HHT provider] job is to take care of dad." so I haven't really talked to anyone at hospice." Another 18-year-old daughter whose mother had lung cancer distanced herself from the HHT noting, "I don't ask them for anything; they are not here to take care of me." For one 16-year old whose father had end-stage lung disease the timing of the interaction was an issue. She said "they [HHT] started talking to me about my father and everything and how it is ...and I got really emotional, kind of like I

am now, and, but it was even worse because it was closer to the time when they first told us, and that is, that's when I said I didn't really want to go to any support groups because I didn't want to cry all the time." Some of the teens did not seem to know what to say to the HHT or how to initiate an interaction. One 16-year-old boy said, "Most of the time I am really just quiet, like I don't say much." Some teens did not wish contact with the HHT. A 16-year-old boy whose father died three weeks after the teen was interviewed said that he did "not really" want to talk to the HHT.

Some teens in this group indicated that they wanted help from the HHT but could not clearly articulate what kind of help they wanted. When pressed, one 17-year-old son indicated that he and others like him really need "a lot of support," though he was unable to say what type of support he would have found helpful. Another 17-year-old son with an ill father who was in the in-patient hospice unit acknowledged the need for support, information or guidance but he did not receive any such help from HHT.

In-Passing Interaction

Six sons (15, 16 or 17- years old) and one daughter (16- years old) were considered to be in the "In-Passing Interaction" group. They had only brief or transitory contact with the HHT, but the adolescent did not describe the interaction as making a connection or receiving support. Like with the prior group, several teens in this group had limited interaction with HHT because of scheduling. A 16-year-old son who provided much physical care for his ill father said, "Usually I am out of the house by the time he [the nurse] comes." A 17-year-old son whose father was at hospice inpatient facility echoed a similar experience: "I was just leaving and she [HHT] was just coming in to roll my dad over and do whatever and change his things and give him his medication and stuff..."

Again, often teens did not seek contact with the HHT because they believed the providers were there only to deliver care for the ill parent. A 16-year-old son whose father was dying of ALS explained, "They come in, they say hi, they really haven't asked me any questions or anything like that." Another 16-year-old son whose mother was dying of cancer said, "Um yeah, we talk about a few things, they [HHT] said a few questions to me, I mean, I don't know what they said, but um we had a few [words exchanged]".

Some teens in this group received updates from the HHT on the parents' healthcare routines and procedures, but the providers did not check to see how the teens were faring. One 17-year-old son said, "I catch just the ending of it and they pretty much just talk about how like it is going to work out with him...and all of this, but that is all I pretty much know about hospice." In-passing interactions, although brief, allowed some teens to determine whether they liked the HHT or not. One 15-year-old son whose father had a brain tumor said, "When I was there [inpatient hospice facility] I would see them [HHT] come in and I knew which ones were the good ones, which ones were the grumpy ones, which ones were the happy ones." One 18-year-old daughter whose mother was inpatient described her interactions with a variety of nurses. "...the nurse that was standing next to you, I really like her because she is all happy and chipper. But the nurse that is taking care of my mom right now with the shorter hair is a very forceful individual; I don't like that she tells my mom what to do."

Some teens' need for information motivated them to seek out the HHT. One 12-year-old son whose father had just been admitted to the in-patient facility for symptom control reported that he went directly to a nurse and inquired about his father's status. He said, "Umm, well, just a couple of days ago when he was in there [in-patient facility], I was really curious, like everyone was. I asked the nurse how much time he had and I got really mad because the nurse only said 'maybe if he is lucky 3 weeks.'" The teen had not been informed by his family that his father, who died 6 days later, was this close to death.

Some teens indicated that they wanted more than in-passing interactions with the HHT. One 16-year-old son whose mother was dying of cancer said, "I guess you can say I have a good contact [with the nurse] but I would like better, ...you know how they have that thing, the button for old people when they fall on the ground, something like that to contact them..." A 16-year old whose father was dying from a brain tumor said "I feel like they [HHT] could've been more there for me, but only if I would've prompted them [HHT]. I feel like they [HHT] were willing."

Engaged Interactions

Six adolescents, four daughters (ages 14, 16, 17, and 18) and two sons (both 16-years- old), were considered to be in the "Engaged Interactions" group because they reported positive, ongoing contact with one or more of the HHT. The encounters between the teens and the providers in this group entailed more than brief exchanges or the gathering of first or fleeting impressions and included meaningful or helpful interactions.

Some teens reported finding a common ground with a HHT provider based on perceived shared similarities. One 14-year-old daughter, for example, spoke of wanting to work in healthcare and connecting with the HHT provider on that basis as the teen talked with the provider about the provider's career in nursing. Other teens indicated that they became engaged with the HHT due to the provider's appealing personal characteristics. A 14-year-old daughter stated, "She [the nurse] is really funny, so we just all come down here and joke around." Or a 14-year-old daughter said that when the nurse came to see her dad, the nurse had a light- hearted manner and teased him about taking his meds. "Yeah, she [nurse] is funny—no only means maybe or later. I like that. She is cool." Other teens were drawn to HHT providers whom the teens perceived to be helpful and accessible. A 14-year-old daughter stated "They [HHT] gave me a hospice bookI will [ask] them a question, they most of the time, 100% of the time, they answer it." One 16-year-old son described one nurse he interacted with on multiple visits that was helpful in more than one way. "She was really helpful; her and my dad were always joking around, which was nice to see. ...She showed me a lot with my dad, how to help him. "When asked if the HHT provided any emotional support he said "she always told us if we needed anything to call her or if we needed someone to talk to, just um talk to her. I never did but I always got, I know that she was there if I ever had any questions which was nice."

Some teens became engaged with the HHT because the providers established a sense of trust. A 14-year-old daughter stated, "The hospice people, they are there to help you. They will answer any question that you have for them..." Some teens formed what they perceived to be a close interpersonal relationship with a HHT member. One 14-year-old daughter

explained, “Sometimes when I come home from school, they are here, and I am like ‘Hey mom,’ and I am like, I don’t know, they [the HHT] are like my second mom, like all of them...” Another 16-year-old daughter whose father had end-stage pulmonary disease felt very close to the hospice nurse. She stated, “It is good to have that connection with someone as in a way, she is like sunlight to all the darkness because when she comes, it is so happy... She is a person I feel like I can depend on.” Or a 14-year-old daughter whose dad was dying from cancer said “they will sit down and talk to me sometimes if they feel like I am feeling down.” One of the teens who participated in after-death interviews shared more openly about his rapport with HHT. “He [HHT provider] was in particular who I communicated with a lot more, not just because I saw him at the school [both teen and HHT provider attended the community college] but I feel like he was there and the role that he served was seeing what he could do to help. And so his recommendation was through talking. ‘Go talk to your dad because even if he can’t respond, he wants to hear about your day, about what it is that you’re doing.’ I think that ties back to my understanding to that connection with my dad on an emotional level, on a level of experience, that is something that is valuable and the hospice worker realized that. For a short while that is what I did, I would talk to my dad about my day. And I think that was valuable.”

Formal Helping Interactions

Six adolescents, 1 son (12-year-old) and 5 daughters (ages 12, 14 and 16), were considered to be in the “Formal Interactions” group because these teens were specifically referred to a healthcare professional to help with the teens’ adjustment to their parents’ illness. Two of the teens were referred to the hospice art therapist; one was referred to a hospice bereavement counselor, one to an outside counselor, one the counselor at the chemotherapy clinic and one was connected to a social worker at a local cancer foundation. The teens in art therapy reported attending sessions and described the drawings they were doing. A 16-year-old daughter whose father had end-stage cardiac disease had an emotional experience with her mother when she shared her painting from art therapy. “It is really fun, [art therapy] but it was hard because my mom cried the first day because I painted a picture of dark colors and then it was like one piece of light and I explained what it meant because it meant like all the sadness and anger that I feel then I feel like there is one piece of happiness, and there is not a lot of happiness...” A 12-year-old daughter working with the bereavement counselor described the games she played with the counselor: “We do this one game and it is a board game and there were four different parts and it was just like questions about what is your favorite memory and stuff with your family...” The three adolescents that were seeing counselors outside of hospice did not offer much detail, though they all felt it was helpful.

Discussion

The present study examined interactions between adolescents living with a dying parent and HHT delivering care. Results indicated that the majority of adolescents reported no interactions or in-passing interactions only with members of the HHT. While lack of contact was often attributed to scheduling because the providers came to the home while the teens were in school, in many cases the teens had no expectations for interaction as they assumed the provider was there only to care for the parent. These findings suggest that the HHT may

be missing important opportunities to assess teens' needs, provide them with support, and refer them to formal counseling or bereavement services if needed.

While many of the teens denied having any needs that the HHT could meet, and several balked at the idea that the providers could be of help to them, the teens' involvement in the research interviews suggest that having someone to talk to might be welcomed with some encouragement and may in fact be helpful. The teens were open to talking with the researcher and most were forthcoming about their experiences, feelings, and challenges. Some indicated that they had not shared their thoughts and feelings with others and appreciated the opportunity to talk with the researcher. Of the 30 adolescents interviewed, 3 shared that they had thought about harming themselves or had harmed themselves. These teens were referred to the HHT.

The participants' examples of engaged interactions suggest that rapport between the teen and the HHT was enhanced if the teen perceived some common ground with a provider or if a provider appeared to be personable, was interested in the teen's welfare, and appeared open to answering the teens' questions. The formal interactions were well received by the participants but how the teens were engaged in these services is unclear.

While the typology presented here needs further development, the findings do have some implications for the HHT committed to a family-centered approach to hospice care. The findings indicate, for example, that some of the HHT visits might need to be scheduled after school or in the evening when teens are likely to be at home. The HHT should be cognizant that even in-passing interactions can affect teens and should remain aware that teens are noticing how the HHT interacts with their parent and may need prompting. Thus the HHT should always appear approachable to teens, even when focused on providing care to the parent, so that positive in-passing interactions may pave the way for engaged interactions.

The HHT might also schedule an initial "meet and greet" with teens to circumvent the notion that the providers are there only to care for the ill parent. Asking parents and other family members in advance about the teen's interests and activities can aid in identifying some common ground to improve chances of making a connection. Pivotal moments in the ill parent's illness trajectory (e.g., disease progression and functional decline) may provide special windows of opportunity to engage adolescents and to develop or deepen relations within the family.²⁷

Finally, the possibility of an additional way to contact the HHT was suggested by one teen. With the age group being technologically savvy, texting or video calls could be added ways for the teen to be in touch with the HHT.

These recommendations are made in light of several research limitations. First, while the teens in the present study appeared open and willing to discuss what it was like to live with a dying parent, they may have still been guarded and withheld some important, personal details about living with a dying parent. To overcome this shortcoming, subsequent research might include a series of interviews with teens so that greater trust can be established with the researchers and dynamic changes in interactions between the adolescents and the HHT over time can be captured. Second, the HHT perspectives on the interactions were not

obtained. Future longitudinal and observational studies that include teen-provider dyads might examine more closely what teens and the HHT do to initiate and develop relationships. Such information can then be used to establish best practices by the HHT for meeting the needs of adolescents when their parents are dying. Finally, hospice care is provided by an interdisciplinary team that meets regularly to assess and evaluate goals of care for patients and families. Team members include (but are not limited to) a physician, nurse, social worker, chaplain, art and music therapist, volunteer, home health aide and counselor. Bereavement services extend for 13 months after death. The configuration of pediatric and adolescent supportive services provided by a hospice may vary which could affect the interactions between the teen and the HHT.

Acknowledgments

Data for this report was collected as a part of research project, "Strategies to Help Adolescents with a Parent in Hospice," funded by the National Institute of Nursing Research [R21 NR012700], Denise Sheehan, Principal Investigator. We are grateful to the hospice staff, patients, and families at Hospice of the Western Reserve for their support and cooperation in helping to complete this study.

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Figure 1. Study Participants

Table 1
Participant Characteristics

	Adolescents N=30	Ill Parent N=11	Well Parent N= 20
Gender			
Male	12 (40%)	6(60%)	4 (20%)
Female	18 (60%)	5 (40%)	16 (80%)
Age (years)			
Mean	15	55	50
Range	12-18	40-62	34-60
Religious Affiliation			
Catholic	9 (30%)		
Protestant	6 (20%)		
Jehovah's Witness	1 (3%)		
None	4 (14%)		
No Response	10 (33%)		
Race			
Caucasian	22 (73%)		
African American	5 (17%)		
Mixed Race	2 (7%)		
No Response	1 (3%)		
Current Family Annual Income (n=26)			
Under \$10,000	5 (19%)		
\$10,001-\$30,000	5 (19%)		
\$30,001- \$50,000	4 (16%)		
Over \$50,001	7 (27%)		
No Response	5 (19%)		
Diagnosis (n=26)			
Cancer		21 (81%)	
ALS		1 (5%)	
MS		1 (5%)	
Pulmonary Disease		1 (5%)	
Mad Cow		1 (5%)	
No Response		1 (5%)	
Time from Interview to Parent's Death (days)			
Mean	41		
Range	0-183		

Note: The ill parent in 4 families died within one week of the interview. One parent died during the adolescent's interview.

ALS=amyotrophic lateral sclerosis; MS=multiple sclerosis.