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A program of the
National Hospice and Palliative Care Organization



ChiPPS Pediatric Palliative Care Newsletter Issue #9; November 2007

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Perspectives of Fathers and Other Males

Welcome to the ninth issue of the ChiPPS electronic newsletter. This e-newsletter links to a PDF collection of articles contributed by a number of our colleagues in the field. The newsletter is produced by ChiPPS (the Children's Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by NHPCO's Education Work Group, co-chaired by Christy Torkildson and Mary Kay Tyler.

Comments about the activities of ChiPPS, its Education Work Group, or this issue of the newsletter are welcomed. We also encourage reader suggestions of topics, contributors, and specific ideas for future issues of this newsletter. Please contact Christy at ctorkildson@georgemark.org or Mary Kay at mktyler@hospicewr.org.

(Click on the "bookmark" tab on the left-hand side of the PDF document for links to the following articles.)

Issue #9: Perspectives of Fathers and Other Males.

A collection of articles on the perspective of fathers and other males as they experience life and death with children.

Give Up or Give Back: A Father's Perspective on Death

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Scott Newport

Scott, the father of Evan, poignantly describes the reality of living day to day with a chronically ill child. One night while Evan was close to death, Scott and his wife needing sleep, leave Evan to the care of his nurse. They each pray silently for Evan. The next day, Scott wakes to the realization that Evan has made it through another rough night and discovers that his silent prayers for Evan are different than his wife's.

The Challenges of Providing for the Family throughout the Course of a Child's Life-limiting Illness

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Rachel B. Levi, PhD

Ms. Levi acknowledges and describes some of the challenges that fathers face as they attempt to provide for their families throughout the course of a child's life-limiting illness. Ms. Levi points out that the impact of this crisis on fathers deserves close care and consideration by pediatric palliative care providers.



Expression of Emotion by Fathers of Seriously-ill Children

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Betty Davies, RN, PhD, CT, FAAN

Maria Gudmundsdottir, RN, PhD, CT

University of California San Francisco

Although studies suggest that there is a gender difference in the way in which women and men express their emotions, the authors of this article caution health care professionals to avoid stereotyping the behavior of fathers. Instead, through case illustrations illustration of how fathers can express their emotions, pediatric palliative care providers are encouraged to help create environments that are supportive of this expression.

A Father's Experience of Neonatal Loss

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Louis A. Gamino, PhD, ABPP

Biennial Scott & White Bereavement Conferences

Fifteen weeks into their pregnancy, Mr. Gamino and his wife receive the heart breaking news that their son has trisomy 18. Mr. Gamino describes the many emotions, dilemmas, and decisions that needed to be faced during the remainder of the pregnancy. In addition, he takes us through the first five months of his mourning. Mr. Gamino offers insight into the journey of a father with the hope that readers who have lost a child will be provided some comfort and that others will be able to better support bereaved parents.

Relating to Fathers in Pediatric Palliative Care: Frequently Asked Questions

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Donna Armstrong, MSW, CSW, and members of the Daniel's Care Team at

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Team members of a pediatric hospice program were surveyed to explore what kind of contact the team has with fathers and observations about this contact. The survey is meant to encourage pediatric providers to examine ways in which they can engage fathers more.

Why Aren't You Crying? Understanding the Instrumental Griever

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Terry L. Martin, PhD

In previous work, Martin and Doka have identified two basic grieving patterns: the instrumental and intuitive styles. In this article, Martin briefly reviews both styles and indicates that males tend to react instrumentally to loss. However, he stresses that the different patterns are gender related, not gender determined. The first step to finding the right resources and methods to help individuals move through a loss is to understand these styles.

TWO POEMS FROM KATI'S FATHER

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After the death of his daughter, a father offers some reflections through poetry.

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Intermountain Homecare

Listing of educational resources focused on the perspectives of fathers and other males regarding loss and grief.

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Give Up or Give Back: A Father's Perspective on Death

Scott Newport
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On a frigid February night, our home echoed with heartbreaking moans. Our boy Evan, only four years old, was dying.

Since before he'd been born, we knew this day would come. You see, Evan was born with a terminal heart disease called hypertrophic cardiomyopathy and a variety of other complications brought about by a genetic condition called Noonan's syndrome.

As he lay dying, medicated with morphine and Ativan for pain, my wife and I both said silent, separate prayers. I imagined our prayers finding their way through the snow-covered roof and jumping from one star to the next, looking for an answer.

My wife, Penni, and I had been here before. This wasn't the first time Evan had been close to death. By that time though, we had learned that we couldn't afford to stay up all night with him. We have become so financially burdened that I must go to work in the morning, which means I've got to get some sleep. And Penni has to mother our other son, Noah, and be Evan's caregiver during the daytime hours; she, too, needs her sleep. We knew that Evan's night nurse would call us if needed and so, unbelievably, we headed off to bed. It's the way we must live in order to survive.

I didn't sleep very well that night but, when I awoke the next morning, relief that I hadn't gotten "the dreaded call" from the nurse flooded over me.

Penni was already downstairs in Evan's home ICU, helping the nurse give morning meds. Their voices seemed upbeat and the medical alarms were silent, so even though Evan was obviously still very ill, it seemed as though he would make it through another day. The smooth sound of the ventilator pulsing away comforted me. I headed off to the kitchen.

Pushing used syringes out of the way, I began to get Noah's breakfast ready. "Noah," I yelled, "it's going to have to be frozen waffles again."

"Fine. Could you cut them up like Mom does?"

It had turned out to be just another morning after all. My silent prayer from the night before – "Oh Lord, please heal Evan's heart and lungs and help him pull through this night" – had been answered.

As Noah happily ate his waffles, I walked back to Evan's room and overheard Penni telling the nurse that her prayer from the night before had been: "Dear Lord, please don't let my baby suffer anymore. Take him and comfort him in your loving arms."

I couldn't believe what I'd just heard. I stood, stunned, in the doorway. I wanted to blurt out, "Why would you pray that?!" but I bit my tongue and decided to leave for work instead. Before leaving, I peeked in again on Evan and, through the tangle of tubes and wires, I saw the one "normal thing" attached to my son – his little blanket, made of a soft cuddly material with a head of a bunny. I kissed him on the forehead.



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"I won't be far from the house today, so don't hesitate to call if you have problems with Evan," I told Penni and the day nurse, who was just arriving.

As I drove my truck to the first job site of the day, I puzzled over the radically different prayers that Penni and I had uttered in the midst of our darkest hour. In fact, all that week, I thought and prayed and soul-searched about it. Finally, I did come to see her point. What I viewed as "giving up," she saw as "giving back"...giving Evan back to heaven.

And even though I can see her point, there's a part of me that just isn't ready to let him go – even to heaven. I think about all the father-son moments that we'll never experience together. I will never teach him to drive a stick shift. I'll never witness him walk across a stage holding his high school diploma. I'll never watch with pride as he becomes a dad himself.

And I wonder how I, myself, am doing in this business of fatherhood. Many times, I feel pathetic that I can't make enough money to give my family everything they need. I can't even afford to buy a cemetery plot. There's an understood responsibility that I – as husband and father and provider – should be able to take charge of the situation and make everything better. But I can't. I try, but I always fall short.

From time to time, social workers come out to the house. They counsel Penni about the stress and strain of parenting a terminally ill child. They talk with Noah about what it's like to have a sick little brother. I'm not sure why they don't approach me as well. I've learned that for me – and for other dads I've talked to – it's difficult to get help, support, and comfort.

You can ask a minister, and he'll offer to pray for you. You can ask a doctor, and he might write you a prescription. You can ask a friend, but he'll end up crying more than you. The closest I've come to finding someone who truly understands is my own dad. He has a big stake in all this too; after all, Evan is his grandchild. He knows that he'll never teach Evan to fish or take Evan to his first baseball game. As Evan's grandfather, he gets it.

And yet, I'm still alone in many ways. I feel that it's up to me to hold it all together – the family, the marriage, the finances, the future. After five years of life with Evan, we've adjusted to the daily routines, the inevitability of his condition, and the reality that life must go on. Even on a night when he could slip from this life to the next, we can't afford to stay up with him. This harsh truth has become normal to us. Living life with a dying child who is, for now, still alive has become normal. The scariest thing of all is wondering what's going to happen when he dies. Will life be better? Will life be worse? What will "normal" look like then?

Picture a band of soldiers, camped behind enemy lines on the night before a big battle. The soldiers are playing cards, cracking jokes with their buddies, and acting like everything is fine. But inside, every man on the field knows that in tomorrow's battle, he'll face death. In fact, he knows that at any moment, the camp could be ambushed, and everything would change in an instant. But on the eve of disaster, a little normalcy, a little laughter, a little denial helps you get through it, helps you survive. That's what it's like to live at our house.

In our house, Penni and I don't always see eye to eye when it comes to Evan. But at the end of the day, we agree on the most important thing. It was best said one evening around a dinner table at a formal occasion. A distinguished older gentleman leaned over and softly asked Penni, "If you could go back, knowing what you know now, what would you change?"

She took a deep breath and said, "You know, I wouldn't change a thing. Scott and I love Evan just the way he is. Yes, he's sick and has all kinds of problems, but he's our son, and he's taught us so much



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about life and has given us joy that few people know. We prayed before Evan's birth for the Lord to give us a healthy child, but God had a bigger plan for us. He gave us a son who loves completely and is loved by many."

No one at that table had a dry eye. Not even me.



The Challenges of Providing for the Family Throughout the Course of a Child's Life-limiting Illness

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Practitioners working with families of seriously-ill children understand that the illness, treatment, and eventual death of a child usher in profound changes in the lives of the parents. Earning an income and providing health coverage for the family take on new meaning when you have a child who is critically ill. This role often falls to fathers. The provider role provides one vantage point from which to consider the multitudes of changes, challenges, and transformations that fathers face throughout the child's illness and decline.

Challenges

Parenting a seriously-ill child requires attending to and balancing responsibility for the "normal" functioning of the family system and siblings of the ill child, the ill child's treatment and needs, and the family's financial needs, including health coverage. Fathers often assume responsibility for this balancing and have described it as difficult and exhausting (Brody & Simmons, 2007; Patterson et al., 2004). At a time of terrible emotional stress, fathers often struggle to learn and carry out previously unfamiliar household and parenting roles.

This balancing occurs in the context of professional responsibilities. A father's career is often a source of identity, purpose, and thus, value to paternal functioning and health. Yet a father's availability, concentration, energy, investment, and participation in the workplace are limited by demands of the illness.

These limitations add another layer of stress for fathers. They may feel guilt when their contributions to the workplace change, and on the flip side, regret that the time that they are required to spend at work detracts from the time that they spend caring for their ill child and with the family (Brody & Simmons, 2007; Kazak et al., 1995). This juxtaposition occurs with anxiety for some fathers about the stability of their job. While flexibility of the work place decreases some of the burden on fathers, the multiple unanswerable questions—like "What will be the course of my child's illness?" "When will he start to decline?" "How much longer will my child live?"—often weigh on their conscience.

These unanswerable questions may also leave fathers feeling conflicted about the choices that they make. For example, many parents report a heightened sense of clarity about "what matters" as they endure their child's illness. However, the financial responsibilities and need for health coverage often leave fathers unable to make changes and to live consistent with this renewed awareness, and may later cause regret.

Other fathers increase their investment in work, citing it as a means of coping, a way to care for the family, and/or an obligation. Such decisions may result in marital distance and/or discord, as mothers may feel that the father is avoiding the illness situation and/or providing them with insufficient support (Patterson et al., 2004).

Whether fathers engage or disengage from their professional environment, many fathers feel distant from one domain of their lives. More specifically, fathers who decrease their time on the job may experience a sense of distance from the job and their professional role. Fathers who become increasingly engaged in or maintain their normal commitment to work have reported feeling distance from their child's medical care, from the day to day caring for their child, and from their ill child (Chesler & Parry, 2001).



Gifts

Despite the above mentioned pressures associated with the provider role, being the provider provides fathers a way of caring for, nurturing, and protecting their families, which may help fathers to cope with the profound sense of helplessness that parents experience in the face of their child's serious illness (Reay et al., 1998, Davies et al., 2004). The structure and familiarity of their job can be a remedy for the uncertainty that enters the family's daily life when a life-threatening diagnosis is given. Fathers also experience a sense of accomplishment and pride—the fruits of their labor are critical contributions to the stressed family system. Finally, providing may yield a way to take their minds off the vast impact of the illness upon their child and family (Brody & Simmons, 2007).

Providing for the provider

Across the course of a child's illness and death, the provider is placed in the position of needing care and consideration (Davies et al, 2004). The challenges imposed by the provider role warrant such consideration. Following the child's death, parents experience a "crisis of meaning" as their assumptions of reality are destroyed (Wheeler, 2001; Woodgate, 2006). The impact of this crisis on a father's professional standing, identity, and commitment deserves close care and consideration.

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EXPRESSION OF EMOTION BY FATHERS OF SERIOUSLY-ILL CHILDREN

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A basic principle of pediatric end-of-life is providing family-centered care that takes into account both the common and unique needs of families and individual family members when a child is dying from a life-limiting condition^(1,2) and following the child's death. Previous work has focused on mothers' experiences⁽³⁾ and siblings' ⁽⁴⁾ experiences, but because little attention has been directed to learning about the experiences of fathers when their child is seriously ill and dies, our study⁽⁵⁾ addresses the critical need to improve pediatric palliative care by developing a better understanding of the experiences of fathers whose child has died.

Studies suggest that there is a gender difference in the way in which women and men express their emotions^(6, 7). Generally, women are perceived as talkers who are quite able to express their emotions, while men are considered to be quiet about and even stoic in terms of their emotions. Rather than openly expressing feelings of sadness and distress, men are more likely to become active and keep themselves busy by working long hours and/or physically exhausting themselves through participation in various sports⁽⁸⁾.

Many of the fathers in this study fit this common perception of men as dispassionate or private, particularly about their sadness and loss. Mike, for example, who lost his 12-year-old son, Alex, to brain cancer, has never cried. He sometimes wants to cry but as soon as he feels his tears approaching, he "shuts it off" by changing his thoughts, talking through it, or going somewhere else. He does this without consciously realizing that he is shutting his tears off. When he was asked how and when he had learned to prevent himself from crying, he said, "I guess we were brought up that guys never cry." Although Mike has never expressed his sadness by crying, his strongest emotion has been one of anger. When he realized that further cancer treatments would be futile, he became very angry and strongly felt that he had lost a battle, the battle with the cancer. At his son's deathbed he angrily "chewed the cancer out" and in a "rough voice" said, "You finally won. I hope you're happy with what you have done." As so many other fathers, Mike felt that he needed "to be strong for everybody else" and even after four years have elapsed since the death, he "still put[s] on that front."

Anger appears to be one of the few emotions that most men can freely express. Pollack⁽⁶⁾ claims that historical, cultural, and economic forces have affected parenting styles in such a way that as boys, men will suffer a traumatic disruption of their early holding environment. This premature psychic separation from both maternal and paternal caregivers may later become problematic for men as they unconsciously try to protect themselves from further loss by blocking expression of all strong emotions except anger. Consequently, according to Pollack, men's ability to grieve and mourn is impinged as they have an inability to tolerate feelings of vulnerability or to express and bear sadness. Cook⁽⁵⁾ believes that men's emotional life consists of the tension between the need for expressing unhappy feelings and fear of the consequences of doing so. Hence, their coping strategies which commonly emphasize suppressing



and blocking of thoughts about the death, controlling upsetting emotions in order not to hurt others, and earnest attempts to deal with their wives' need for their husbands expressiveness.

Nevertheless, individual fathers differ in how they respond to the illness and loss of their child. It is clear from our study that some fathers do emphasize the importance of talking about and expressing their emotions as a way of facilitating their own healing. For example, George insists that talking about his emotions helps him in any situation because by talking he thinks that he is more likely to gain insight into his own emotions. By gaining insight into his emotions he believes that he will increase his self-understanding and ability to help himself and others. He said:

I know for me, any situation or any time that I'm able to talk about it, or express to someone, it helps me out. It helps me to, "Oh, I really didn't think about that at that time". And I really like it when I get a revelation like that because it puts me more in touch with my real feelings and how, hopefully it'll help me out, help me to help my children.

And that's a quality that everyone doesn't have, it's the ability to express themselves. It's easy to hibernate from it. It's easy to shut off the pain and not deal with it. But are we not dealing with it when we shut it - or think that we're shutting it out. How much are we tearing ourselves apart by not being open about it? I know for me it hurts more when I'm not able to share how I feel – not necessarily just about this situation, but anything. When I'm not able to say, "You know honey, that really didn't make me feel good when you did that." It makes me feel better now that I'm able to share it with them [his family].

During Sadie's illness, George and his family regularly held an open forum or a family devotional time. In those meetings, family members prayed together and they were encouraged to openly express their feelings. George described these family times:

... our family devotional time, we were consistent on having. One night we had family devotional time where we all prayed together, we all spent time together talking about our dev-, how our feelings and getting open about our feelings helped us out in a lot of those times because it was an open forum. It wasn't a critical time where we tried to justify our things, our actions. But just more time allowing our feelings to [be] openly aired and expressed. That helped [Sadie's older sister] a lot of times because I think she felt she looked forward to that time to be able to express what was on her mind. And we tried to implement those [meetings].

George's strong faith and his supportive church community may have facilitated his ability to organize and hold family devotional meetings. As a family, they were used to praying together and talking to God even before Sadie's illness. Their strong belief in a Christian God allowed and encouraged them to honestly and freely express their thoughts and emotions to Him who they believe loves them and knows what is best for His children.

Early on during Daniel's illness period, Andrew believed that he needed to be strong, resourceful, and confident for his family. However, he also realized that the difficult challenge of illness might destroy his family. As he became aware of this threat, he discovered that he needed to talk about his experience with others. Moreover, he found out that his wife needed him to be able to show his fears, worries, and sadness as they endured this challenging time. He said, "I learned to get over my sort of rock of Gibraltar routine. But I also did still have to be...strong and resourceful."

Andrew's way of dealing with his newfound need to talk was by making everyone he met and who was brave enough to ask him about how he was doing, into his "therapist." That is, instead of saying that he was doing fine, if he wasn't fine, he would tell whoever asked, exactly what was troubling him:



Every person I talked to everyday became my therapist. If they made the mistake of saying, "How are you doing today?" [Laughs]. You know, I didn't just say fine, if I wasn't. You know, if I had something to talk about, or if there was something that was bothering me, or if we had a problem with Daniel, or with the hospital, or whatever. I found I needed to not hold it in, in that way. Partly because I felt, particularly in the beginning, that I needed to be strong, and resourceful, and confident for my family because I could see that it was quite possible that this would destroy us. That [my wife] might have a nervous breakdown, or my kids, or the other kids might freak out, or run away, or turn to drugs or something, you know. So, I learned in time that I, not only could I talk about this kind of stuff with [my wife], but I needed to talk about it. She needed me to show her my fears, and my worries, and my sadness, and that kind of stuff...so I had to process my "stuff".

Andrew and George were talking about sharing their thoughts, expressing their emotions, crying freely, sharing the burden through asking for and accepting help. It had been a struggle for them to learn to do this, but they felt they had succeeded in learning new ways of coping and were happy about the changes that resulted. Some might conclude that what these fathers learned to do are characteristically women's ways of coping. Indeed, it seems that women express emotions and tears readily. But, not all women, and not all mothers of dying children. For example, in an interview from another study with a family where the focus was on the sibling's response to her sister's death, the mother and father agreed that their "roles should have been reversed." The mother explained:

I should have been the guy and he should have been the woman because it's like he needs that talking. I have the network and I don't use it, and he would love to have the network but he doesn't have it [with the other guys].

There is no doubt that men and women are different in how they respond to the world. Sam Keen⁽⁹⁾ suggests that the reason for the differences has to do with our time in history. We are the products of an historical era in which men have been socially assigned the chief roles in warfare and the economic order. Many of the personality characteristics that have been traditionally considered masculine – aggression, rationality – are not innate or biological components of maleness but are products of this historical era. The unexamined life has been worth quite a lot in economic terms, resulting in men having to carry a special burden of unconsciousness, and of ignorance of the self.

However, says Keen⁽⁹⁾, there is a new world order emerging wherein our old models of manhood no longer fit our expanding knowledge of the way things are. He refers to Joseph Campbell's description of the journey of the "hero with a thousand faces" (p. 127) as a magnification of the formula represented in the rite of passage: separation–initiation–return. It is a process of transformation that requires a destructuring of the old self before constructing a new identity; it requires a pilgrimage into the depths of the self.

The fathers in our study referred to their learning to cry and to express their thoughts and emotions. It was a way of learning how to cope with the spiritual or existential pain of caring for a dying child, and of coming to terms with the fact that life goes on after one's child has died. As Keen⁽⁹⁾ says, "the path to a manly heart runs through the valley of tears" (p. 135). These fathers had overcome the cultural stereotypes of always needing to be in control, in charge and responsible for whatever happens. By avoiding stereotyping the behavior of both mothers and fathers and by accepting the individual coping styles of each individual father, health care professionals can help create environments supportive of the expression of emotion by even the most stalwart fathers.



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A Father's Experience of Neonatal Loss

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This article originally appeared in The Forum Newsletter of the Association for Death Education and Counseling (ADEC; adec.org), the Thanatology Organization, in January/February 1999 and is reprinted here with permission of the publisher. It was written approximately five months after the death of our baby in 1997, now almost 10 years ago. My hope is to sensitize readers to the dynamics and effects of neonatal loss, as we experienced it, in the interest of furthering death education on this subject.

"There's a problem with the baby." These warning words from the doctor at the 15-week sonogram meant immediate alarm. He had detected structural defects in the baby which changed my outlook on the pregnancy from joyful hope to morbid fear. Subsequent testing confirmed the diagnosis of a chromosomal disorder, trisomy 18, meaning there had been an improper disjunction of the chromosomal material at the moment of conception. In essence, this laid down a faulty genetic blueprint for the cells that built this baby. The most serious anomaly was a heart defect that was judged to be irreparable and thought to be fatal. The prognosis was that our child would likely not survive.

We also found out our baby was a boy. We named him Anthony Francis.

I felt helpless, aggrieved, boggled and dejected. Most of all, I felt afraid. No one could tell us anything for sure. Being information-seekers, we obtained literature and articles on this particular genetic condition. The journal articles showed clearly that many parents terminate the pregnancy when this devastating diagnosis is made. The prognosis was described as "incompatible with life."

The initial dilemma we faced, to terminate the pregnancy or to continue, was resolved by listening to the principles of our Catholic faith: God is the author of life and we are the stewards. Life should be nurtured not taken. Since we had accepted the role of parenthood when we had begun trying for a third child, we decided to "see it through," whatever happened. Adding to our decision was the fact that Marla had already felt the first quickening movements of the baby. We knew he was alive.

At the same time, our faith allows that should the end of natural life be near, heroic measures to prolong it are not required. Since little Anthony's heart defect would prevent him from oxygenating blood on his own, resuscitation and respirators would be pointless. I found some small measure of comfort in knowing that we need not apply every marvel of modern neonatology if our child may only live a short time. So, we elected "no treatment" at his birth. Whatever time we would be given with Anthony, we would simply hold him, try to make him comfortable and love him.

Yet, "seeing it through" meant perhaps going a full term pregnancy with a baby that may be stillborn or at best live maybe a few hours or days. I'd heard of such sorrowful situations but never personally known of one. Now, we were living it. We prayed. But we did not pray for things to change (e.g., "a miracle") as did some of our friends. Instead, we prayed for the strength to cope with what was to come.

The five additional months that Marla carried Anthony were full of anxiety and anticipatory grief. It was like looking down the barrel of a gun you know will ultimately discharge. Not only was death coming, it had already invaded our household, our consciousness and stealthily infiltrated the rhythm and course of our lives. Casual observers would ask about the pregnancy and it was mostly what *wasn't* said, the excitement that *wasn't* expressed, the sadness that *was held within* until the subject could be mercifully changed to something else.



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Much of my own negative emotion I tried to channel into planning and preparation. No doubt I was seeking what has been called “symbolic mastery” over death by controlling those circumstances and conditions which I could (Doka, 1984-85). We were jealously protective of what would happen to our son. We interviewed funeral directors to find one who would cooperate with our doing almost everything ourselves, even down to using our own minivan as a hearse. A great deal of time was spent selecting an acceptable coffin. Marla began work on an elaborately smocked burial gown. The funeral liturgy was orchestrated in great detail. I wrote the obituary for the newspaper. We decided to hold the visitation hours in our home since that would be only time that little Anthony would be “home.” And we felt very strongly the need to bury our son ourselves, by hand, rather than leave that final task to a cemetery worker. These things were a labor of love we wanted to do and the work of grief we needed to do.

We told our two children that the baby was “sick” and probably would not come home from the hospital. Their biggest concern was whether or not they’d get to play with the baby. In talking about Anthony’s likely death with them, we shared our own disappointment and sadness. We all became more aware of cemeteries.

The process was not without protest. I was angry. Why us? We’d be good parents. I felt robbed. Others our age were having healthy babies, why shouldn’t we? It was hard to be around small infants yet at the same time I held every one I had the chance to.

My anger and bitterness smoldered until I attended a Church retreat in the seventh month of the pregnancy. There with the compassionate help of two men who had themselves lost children, I confronted my fury. I was able to admit to myself that the son I had been given, with fatal medical problems, was *not* the son I had wanted. And I realized that in lamenting what had gone wrong with the pregnancy and *what might have been*, I was missing the fact that Anthony was alive at that moment. I began transforming my “meaning-making” (Nadeau, 1997) about the pregnancy. Rather than seeing it as a probability-based medical mishap related to maternal age, I began to think of Anthony’s conception as a living testament of God’s procreative power, not just a tragedy. Anthony was alive at that moment and his life was deeply affecting me and touching everyone who became aware of the situation. I also vowed to accept with grace and dignity the sorrow involved.

When Anthony Francis was finally born, alive, we had just enough time to baptize him, hold him and take pictures. He was surrounded by the love of his parents, his brother and sister, his godmother, and all four grandparents. He only opened one eye and moved just a little. Anthony’s death was peaceful. He slipped away quietly in the wee hours of the night with Marla holding him.

The nursing staff was very respectful and gave us the latitude we needed at such a vulnerable time. After keeping Anthony with us for another three hours or so, to bond and to grieve, we knew it was time to release him. I carried him myself through the deserted hospital corridors and entrusted him to our funeral director. He never went to the morgue.

The following day we dressed Anthony in his hand sewn burial gown and each of us put a gift in his casket before we closed it. The children gave him toys and pictures. I enclosed a “goodbye” letter. Both children became distressed at the finality of this. My daughter sobbed and my son, reacting to her emotion, asked poignantly, “Why won’t he wake up?”

Just as Marla had safely carried Anthony Francis for 38 weeks while he was alive, I now carried him in death. I was the only pall bearer he required at the Church and at the cemetery.



The funeral Mass for Anthony was beautifully done and gave comfort in its liturgical elegance and its theological familiarity. I found solace especially in the music. Fortunately, many contemporary Catholic hymns are both scripturally-derived and emotionally sensitive. Consider the words of the recessional we chose by Marty Haugen (based on 1 Corinthians 2:9-10), "Eye has not seen, ear has not heard what God has ready for those who love him...Our lives are but a single breath, we flower and we fade, yet all our days are in your hands so we return in love what love has made."

Perhaps nowhere did I feel the saving support our family and friends as much as at the cemetery. Somehow our instructions to the cemetery director were misunderstood and, when the moment came to actually bury Anthony, the hole that had been opened was *too small*. Marla and I were indescribably horrified, rendered low by a belly punch when our hearts were already breaking. My brothers holding Anthony's casket were paralyzed. The disbelief suspended all present until, at last, a fellow Church brother stepped forward and began to enlarge the grave with one of the shovels we had brought. My gratitude to this man knows no bounds for his kindness extended at our weakest moment.

Ultimately, everyone helped us bury Anthony. My son did a fair amount of shoveling himself. It was mourning in action. The shoveling was not just ceremonial; we actually "closed" the hole as a community effort. Besides our loss as parents, the loss of our son was also a tear in the social fabric of the community to which we belong. Just as all grieved with us, all helped to "close" the wound. During the final "walk by" to greet the immediate family, each mourner put a fresh flower on Anthony's grave. When we finally left the cemetery, it felt "finished."

Recognizing that I had no energy or empathy for anyone else's problems, I stayed off work for two weeks before going back to my practice in clinical psychology. When I did return, my grief was only just below the surface. I wasn't sure if patients' stories would elicit my own grief emotions rather than an empathic response to whatever pain they were communicating. So, I decided to wear mourning garb--a simple black lapel ribbon affixed by a tiny gold angel pin. Patients sensitized enough to notice would inquire and it afforded me a graceful opportunity for brief self-disclosure. This seemed to inoculate me from "breaking down." Though wearing mourning garb beyond the funeral is not that common in mainstream American society, I borrowed the idea from minority cultural traditions (Braun, 1997; Range, 1995). For a month I wore the ribbon and it proved to be a subtle but effective social signal to others of my own bereavement status.

Marla and I have tried to be understanding and respectful of each other's differences in responding to Anthony's death. We have grieved differently because we each attached differently to him. For me, the relationship was more abstract while for Marla it was more physiologic. Due to his small size and decreased vigor, I only felt Anthony move a couple of times while in utero. I *knew* he was there. However, because his kicks were most often toward Marla's internal organs, she *felt* him there and had a stronger sense of his aliveness. Thus, she could be more joyful when I was more often sad. Being grounded this way, Marla misses Anthony differently than I do and visits the cemetery more frequently.

We also experienced the tremendous power of "reframing" (Framo, 1996). Marla gained an inordinate amount of weight during the pregnancy with Anthony which seemed even more disproportionate given his small birth weight. She was naturally distressed over this and it seemed to add insult to misery. After Anthony's death, I was describing Marla's consternation about her incongruous weight gain to a kindly physician who replied sagely, "Oh, her body was trying to feed the baby." Of course! What we had seen as yet another undesirable side effect was actually a result of Marla's maternal physiology trying to nourish a life that just wouldn't grow. Both of us felt enormously better after that singular comment.



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At the time of Anthony's death, in lieu of flowers we requested memorials to establish a children's library of religious books at our Parish. The funds contributed far exceeded any expectations of mine. Now the organizing, decorating, and stocking of the library room is an ongoing project that gives an outlet for our generativity needs otherwise frustrated by Anthony's death. It is our hope that many children will come to benefit from the donations made in Anthony's memory. This possibility has helped soften the sting of Anthony's death for me.

We continue to engage in a number of other "post funeral rituals" (Bolton & Camp, 1986-87): securing an appropriate monument for Anthony's grave; planting a tree on the Church grounds in his memory; and communicating our experience of Anthony's life and death through efforts such as this article. I expect such mourning work to continue for the rest of my life. I do not consider it maudlin or wallowing in grief. I find it a way to stay connected to my son who was physically with us ever so briefly.

Looking back now approximately five months after Anthony's death, it seems quite clear that our Catholic faith was a central touchstone for our decision-making about the pregnancy as well as for our theological construction of the meaning of death. From these understandings came many of the rituals we incorporated in Anthony's baptism and funeral Mass. At the same time, meaning also *flowed from* many of the rituals we chose such as the visitation at home, transporting Anthony ourselves and the personal burial. As Irion (1990-91) pointed out, funeral rituals have value because they permit mourners to act out symbolic behavior that expresses meanings and feelings difficult to communicate only in words. I feel the totality of our ritual behavior expressed our depth of love for little Anthony.

My four year association with ADEC and the extensive thanatology information to which I have been exposed helped inform many of my own sensibilities and steps in grieving for my son, Anthony. Knowing that we did everything we could for Anthony during the pregnancy and at the time of his birth and death is a strong source of comfort to me now. I believe my knowledge gave me both ideas about how to mourn and courage to follow my feelings even if it was unfamiliar to others or made them uncomfortable. In the end, Marla and I have relied on our personal strengths, our love for each other, the support of our family and friends and our faith in God to see us through. I hope hearing our story, from the father's viewpoint, will be helpful in your advocacy for bereaved parents and for all who grieve the loss of a loved one.

While this essay represents accurately my responses during that acute grief period, much has happened since then. In 2002, together with co-author, Ann Cooney, I published a book about my experience that is intended to comfort parents who have a miscarriage or stillbirth (Gamino & Cooney, 2002). That same year, Marla and I had another child who, because of Marla's age, was truly unexpected. He is now 5 years old and has been a tremendous joy in the aftermath of grief. He is not a "replacement child" but his arrival has afforded us the opportunity for "replacement parenting" which has made an important long-term difference in our lives since Anthony's birth and death. Yet, I fully realize not every bereaved parent's story has a happy "next chapter." I hope that my sharing this reflection will afford some comfort and understanding to readers who have lost a child and will help professionals, volunteers, and family members to better support bereaved parents. Like my book, this article is dedicated to the memory of Anthony Francis and to all other children who die from miscarriage, stillbirth, or neonatal death.



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Relating to Fathers in Pediatric Palliative Care:

Frequently Asked Questions

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How does the hospice and palliative care team relate to fathers of children with life-threatening and terminal illnesses? From experience it appears most of our work may be with the mother as she is most likely the primary caregiver. This is even more likely for teams working with patients and families in their home as the father is usually working. Often the parents are not living together. With the father not living in the home, contact may be even more difficult. Team members were surveyed to explore what kind of contact the team has with fathers and observations about this contact. The survey was anonymous in order to elicit candid responses. Team members replied that this was an insightful exercise which encouraged them to examine ways in which we can engage fathers more.

How often do you visit with fathers?

- Rarely, I occasionally visit with the father of one of my patients when mom is out of the house.
- Seldom.
- Once per month or every other month.
- I visit with the father frequently or occasionally in a small percentage of the families I see. For over half of my patients, there is no contact with the father.
- It depends on the family. Most fathers are not home during the day.
- I generally see the fathers of the patients once every 4-6 weeks.
- In many of my families, there is no father in the home. In the families where there is a father he is often working. I will try to plan and visit with him every other month or so.

Are fathers ever the primary caregiver?

- I have not had a pt where that is the case.
- Not in my experience.
- I am working with one family where this is the case.
- No.
- It is rare.

If the father is the primary caregiver, have you noticed gender differences in caregiving? If so please elaborate?

- Yes.
- Dads seem to be calmer and more matter of fact than moms.
- They either seem to worry less or it shows less.
- The father seems very comfortable utilizing technology/equipment and calling on extended support system to minimize caregiver stress.
- N/A.



If the father is not the primary caregiver, do you or another member of your team make a point of making contact with the father? If so how is this done?

- Yes, I sometimes visit late in the day when I know dad will be coming home.
- We see the fathers because the visit time varies and we just happen to run into them.
- If the father is interested in meeting/talking with team members. Team members usually make adjustments in their schedule to meet with the father, often after hours.
- Usually not. Only if the mother verbalizes problems? For example, stress related to father's different view or degree of denial re: patient's illness or if there are marital problems. I may suggest a meeting with father and mother in order to assess the situation before referring to marriage counseling.
- Sometimes we may have one member of the team, such as the Chaplain, reach out to the father via a phone call. This will hopefully lead to a meeting.
- When the father is present, we make efforts to include/engage him in conversation and give him opportunities to ask questions.
- Sometimes we maintain contact by phone (for fathers who are at work during the day and want contact with team).
- Occasionally, phone calls are made to fathers at work (if work permits this). This can help in establishing a relationship and can lead to some very deep conversations.

Based on your experience, how do fathers seem to cope with the stress of living with a child with a life-threatening illness?

- They let the wife handle most of the care of the child.
- They are mostly nervous nellys.
- Fathers exhibit more stress and more uncertainty. They often cope by working more and staying away from home.
- They tend to cope by concentrating on their work as their way to help the family, keep the medical insurance, etc. Because they don't do the majority of the day to day care, they seem to have a less realistic grasp on the patient's prognosis.
- It appears fathers cope by maintaining as much normalcy as possible.
- Some fathers are actively involved until the child outlives his life expectancy and then they begin to detach.

What concerns/needs do fathers voice to team members?

- The stress of a sick child.
- Mostly "how do I do this?" related to care issues.
- More concerns about medical issues, medicine related questions.
- When fathers voice their need, they tend to deal more with practical or medical needs rather than ones of an emotional nature.
- Insurance coverage concerns.
- Impact of situation on job.
- When will it end?
- Changes in family dynamics, concerns about siblings.



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Are there any creative and unique ways you have developed to engage with fathers?

- (I don't think this is in any way unique.) Once mom has shared issues with me about father (whether it be marital stress or lack of understanding of patient's prognosis), I'll ask mom to have dad keep her company while she talks to me. Usually it happens, that as mom talks to me, Dad becomes engaged and begins to open up about his ideas, worries, concerns, etc.
- Make after hours visits.
- Discuss support received from work.
- Meet the father outside the home for a cup of coffee and visit (perhaps on his lunch hour).

Do you feel more could be done by your team members to engage with fathers? What suggestions do you have?

- I think we already do all we can to engage with fathers. The fact that not many of them are involved has more to do with the fact that they are usually at work while the team is working.
- Perhaps it would enhance communication for team to leave written information and notes for fathers we don't have a chance to see, along with our 24 hour number, if they have any questions.
- More phone calls.
- Learn Spanish for fathers who speak only limited English.
- Make appointments when Dads are home.
- Yes, just engage them about their concerns and questions.
- Yes, I think encouraging regular contact (maybe through bimonthly or quarterly "family meetings") could be helpful in establishing rapport with fathers.



Why Aren't You Crying? Understanding the Instrumental Griever

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Styles of Grieving

Kelly was a bright, mature, and very responsible fifteen-year-old, so when she asked her mother if she could ride to the mall with her friend Angela (18), her mother reluctantly agreed. Kelly did not survive the trip. Their car turned into the path of a fully loaded cement truck. The driver tried in vain to stop but the truck slammed into the passenger side of the car.

Several months after the accident, at the urging of their rabbi, Kelly's parents sought counseling. It soon became apparent that the real issue was the grieving style of each parent. Mother was openly and deeply distressed, crying several hours a day and finding it impossible to return to work. Father had returned to work a week after the accident and outwardly expressed no strong emotional response to his daughter's death. This difference in styles had created tremendous pressure on the marriage with the mother feeling alone, isolated, and abandoned by her husband. The husband could not understand why his wife could not get beyond where she was in her grief.

When questioned about support systems, the mother said that weekly visits to a bereaved parent's support group were the only times she felt understood and supported. Her husband had attended the first meeting with her but found the display of raw emotion too uncomfortable and did not return. He found that being at work and being challenged to solve work-related problems provided an escape from the harsh reality of the loss. He also was proud of the fact that he had replaced the temporary wood cross marking the spot of the accident with a permanent brick memorial.

After learning that the different styles led to the same place—living on despite the loss—the couple was more attentive to their differences and was able to discuss them more openly. Three years after the daughter's death, the couple was deeply involved with the Department of Motor Vehicles in setting up a program that distributed key rings embossed with their daughter's name to all new drivers. The key rings were accompanied by a brief history of the accident and how it might have been avoided.

Martin and Doka (2000) identified two basic grieving patterns: the instrumental and intuitive styles. What follows is a summary of the differences between the patterns.

Intuitive

- Experience grief as intense feelings that are dominant, powerful, and enduring
- Outward expression of grief mirrors the inner experience: The grief expressed is the grief experienced
- Adapt to their losses by going with the experience, seeking to tell and retell the story of the wound
- Not as adept at responding to concrete challenges or problems resulting from the death



Instrumental

- Focus is on cognition
- Do not experience deep feelings
- Challenge is to master feelings
- Don't like to talk about feelings, just issues
- Spend much time problem solving and problem finding
- Less adept at expressing what feelings are experienced

Martin and Doka chose to avoid labeling the differences as male vs. female. This was an important distinction that challenged much of the previous literature on gender differences in grieving which held that women expressed their pain and men avoided or suppressed their own, and since open expression of feelings was considered a healthier response to loss, many men would need help with their grief. Not only was this an often fruitless task, but it sent the signal that intense tears were a necessary prerequisite to healing. An additional risk in assigning different styles to gender was the implied notion that all women are intuitive grievers, and all men instrumental. It is true that most men tend to be more instrumental in their grieving and most women display the intuitive style but there are important exceptions. There are women who do not display open feelings and men who are comfortable in crying.

Martin and Doka remind us that, just as there are no perfect people, there are not people with perfect styles. All of us have our own style that falls somewhere along a continuum from instrumental to intuitive. Most of us are more of one style than the other.

Problems arise when the griever's style is typical of the opposite gender. The following case is illustrative.

Marty and Tom had always felt they were blessed. They were financially secure, had a comfortable home, and two wonderful children. It's not surprising, then, that they felt betrayed when their ten-year-old son, Henry, was diagnosed with a diffuse brain stem glioma. Both parents understood that Henry's chance of survival beyond 1 to 2 years was almost zero but their reactions to the prognosis were very different.

Tom experienced what he termed "an emotional meltdown." He found himself unable to concentrate at work, often going to the restroom to cry. At home, Tom only participated in Henry's care when asked to do so directly by Marty. He spent hours staring blankly at the television screen. He did find some relief by attending the parent support meetings at the hospital where Henry was being treated. At first, he felt awkward sharing his feelings with others, especially since the majority of attendees were mothers. Later, he cried along with most of the others.

Marty, on the other hand, threw herself into Henry's care. She initially spent hours researching the disease on the Web. She eventually found some clinical trials that offered little real hope for Henry's future. When asked about her reactions to Henry's condition, she stated that she was able to "compartmentalize" her feelings from what she knew needed to be done. She also said that she had never "been much of a crier."

After Henry's death the patterns remained consistent, with Tom reacting intuitively to the loss and Marty remaining instrumental. Marty's greatest challenge came from her family and friends who kept warning her that she was going to experience a "breakdown" unless she "got in touch" with her feelings. When that did not materialize, Marty's support network began withdrawing from her.

Ironically, since androgyny has become the standard for the "modern male," Tom received a great deal of support and encouragement from others. Unfortunately, the same standard did not apply to Marty since her response was distinctly "unfeminine."



Providing Assistance Based on the Grieving Style

Since societal expectations lead often to approval or disapproval, intuitive grievers generally find themselves in more comfortable and supportive environments. This is especially true with regard to support groups and systems. Unfortunately, in our society, there are not as many preexisting supports available for instrumental grievers. So while some of the approaches listed below might be valuable to both styles, this section is primarily concerned with addressing the needs of instrumental grievers.

Cognitive strategies are ready-made for instrumental grievers. These strategies can be learned using a variety of resources, including books and professional guidance. They include the following:

- Logical analysis and mental preparation—breaking down the overwhelming crisis into groups of small, manageable issues
- Cognitive restructuring—changing the focus to potential positives associated with the loss, e.g., transformative aspects of the loss
- Cognitive avoidance—developing strategies that enable one to deny, avoid, or minimize the loss
- Information seeking—understanding and validating one's experiences
- Appropriate use of humor

Behavioral strategies, too, are natural responses for instrumental grievers. Examples of behavioral strategies follow:

- Problem solving—planning the funeral, finding substitutes for the loss (not the person)
- Physical activity—may or may not be associated with the loss (digging the grave, establishing a memorial fund, physical exercise)
- Spiritually focused strategies—have the advantage of involving the cognitive, affective, and behavioral strategies (prayer, attending religious ceremonies, planning rituals)

All of these strategies present an additional bonus in the form of “I'm doing something to get back in control of myself and my environment.”

It is important to remember that instrumental grievers do have feelings—it's just that the feelings are not as intense or as important. Since instrumental grievers may not be as capable in processing affect, it is useful to acknowledge the value of affective strategies. These include:

- Ventilation of feelings—especially in safe environments
- Affect regulation—choosing the time and place to share feelings
- Indirect ventilation of feelings—identifying the various ways in which feelings are experienced and expressed (e.g., watching a stirring movie, listening to music)

Regardless of the strategy employed, it is important to be guided by a competent professional since all strategies have both positive and negative outcomes associated with them. For instance, denying the loss may impair the potential for positive action. The inappropriate use of humor can worsen a situation. Ventilating affect without considering the immediate environment can alienate others from the griever and result in isolation.



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Summary

There is little question that the two styles or patterns identified often coincide with a person's gender. However, it is important to remember that while many, if not most, men react instrumentally to a future, present, or past loss, the patterns are seen as gender related, not gender determined. Nor should one forget that the different styles represent differences—not deficiencies. Understanding these two styles can be the first step to finding the right resources and methods to move through loss.

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TWO POEMS FROM KATI'S FATHER

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Kati

Oh what a sweet delicious pain

I now embrace

Don't you see, it hurts so much

Only because I loved her so much

I've been blessed with the tragedy

Of being physically apart

But spiritually joined

I suffer pangs of longing

But celebrate knowing she existed

So when I think of her

I'll have a smile on my lips

A resounding joy in my heart

And tears in my eyes



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STILL MY TEACHER

My precious daughter

Your world turned upside down

And still, you teach me

You have taught me

That you can laugh

Even as the tears flow

You have taught me

That strength

Is not muscle nor bone

You have taught me

That time is not something to measure

But something to live

You have taught me

Not to have hope

Instead to have faith

You have taught me

Winning isn't when you finish

But doing the best with each step you take



SELECTED EDUCATIONAL RESOURCES

Karen Baranowski
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The following resources are specifically focused on the perspectives of fathers and other males regarding loss and grief. It is recommended that you examine a specific title for yourself to determine its strengths, weaknesses, and suitability for those to whom you might offer it.

Website

Ethan's House: The Dads Network
<http://www.geocities.com/Athens/Parthenon/2703/dadst.html>

Books

Angell, J. W. (1990). *O Susan!: Looking forward with hope after the death of a child*. Pasadena, CA: Hope Publishing House. ISBN-10: 0932727395

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Schwiebert, P. (2003). *Strong and tender: A guide for the father whose baby has died*. Portland, OR: Perinatal Loss (2116 NE 18th Ave., Portland, OR 97212). ISBN: 0961519770

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If you have any items you would like added to this section in future issues, please send information to the above email address.