

**GENDER ROLES/STYLES IN CRISIS:  
THE EXPERIENCES OF FATHERS  
OF CHILDREN WITH CANCER**

by  
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**GENDER ROLES/STYLES IN CRISIS:  
THE EXPERIENCES OF FATHERS OF CHILDREN WITH CANCER\***

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## GENDER ROLES/STYLES IN CRISIS:

### THE EXPERIENCES OF FATHERS OF CHILDREN WITH CANCER

#### Introduction

Most of the research literature and informal commentary on the experiences of parents of children with cancer concentrates on samples of mothers and issues faced primarily by mothers. A few studies include a substantial number of both mothers and fathers (Chesler & Barbarin, 1986; Cook, 1984; van Dongen-Melman, 1995), most report data from only or primarily mothers (whether or not they state the focus is "parents" or "mothers"), and almost no work focuses primarily on fathers of children with cancer. Many of the studies that do include mothers and fathers focus only briefly on the gross differences between both parents, and very few detail the specific issues fathers face, or the often different shape that common issues take for them (Fife, 1985; Grootenhuis et al., 1996; Kupst et al., 1984; Peck, 1979). We almost never see or hear the actual voices of fathers or their own articulation of their concerns and struggles, and thus seldom know the common (or unique) nature of men's experience.

Since mothers are the primary caretakers of children, are more easily accessible as research subjects, more typically respond to family-oriented scientific inquiries, and are more often thought of as knowledgeable informants' of their children's lives, they are the most common subjects or informants in these studies. Scientists' choices, or intentionality of design, is certainly one issue: for instance, in a face-to-face interview study of families of children with cancer, Chesler & Barbarin (1986) gathered data from roughly equal proportions of fathers and mothers (60% wives and 40% husbands); in a later mail questionnaire Chesler and colleagues sent to peoples' homes asking for a parent to respond, dramatically unequal proportions of men and women were represented (89% wives and 11% husbands).<sup>1</sup> The combination of these gendered

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<sup>1</sup> The latter work is part of an ongoing investigation of the experiences and outlooks of long-term survivors of childhood cancer and their families (supported in part by NCI Grant #3P30CA46592-10S2).

scientific biases and gendered family dynamics leaves important questions overlooked concerning the experiences of fathers of these children and their roles and contributions in family life.

No claim is made here that fathers experience greater stress or challenge than do mothers as the parents of children with cancer. However, they may face some different stresses, or experience some common stresses in different ways. These differences are due to, and compounded by, the way gender roles are socially constructed and acted on in western societies. Gender, after all, is a mix of an identity held within the body and a role or set of expected behaviors people play out in interaction with others. Viewing people's experiences in the midst of the personal and family crisis generated by childhood cancer provides a dramatic window into general issues in gender roles and styles, gendered family dynamics, and gendered organizational relationships.

## Methods

This paper reports a preliminary exploration of the experiences of fathers of children with cancer, especially their somewhat uniquely gendered experiences. It draws from the minimally available scientific literature, as well as several different sources of data. In several different research efforts we have conducted in-depth interviews with 70 mothers and 40 fathers of children with cancer. In addition, over several years Chesler has conducted 7 "workshops for fathers" at conferences of families of children with cancer (approximately 115 men have attended and participated in these events), and many of them have been followed by letters, phone calls and correspondence. Finally, Chesler is the father of a long-term survivor of childhood cancer, and a member of a family that includes a mother and a sibling of this survivor. Although none of these data sources are "representative" of all fathers, they are instructive and often provide compelling information. Thus, what follows are the voices of fathers of children with cancer as they report or reflect upon their own experiences; on occasion we have introduced reports from their wives, as counterpoints to or elaborations of the fathers' comments.

## What are the major stresses or challenges these men face?

In prior work, Chesler & Barbarin (1986) identified five major categories of stress experienced by parents of children with cancer: informational, practical, emotional, interpersonal/social, and existential/spiritual. It is clear that fathers as well as mothers experienced these stresses, but in the following section we report the particular ways fathers commented on these stresses.

Informational stress includes the encounter with a strange and unfamiliar disease, one without a known cause or consequence.

No one told us the diagnosis.

I found the constant quest for information about my son's disease an ongoing struggle in itself as I searched for some facts about an already grim prognosis.

I was never satisfied that I had all the information I needed to make critical decisions.

Practical stress includes the need to manage work, the family and household chores and responsibilities under very trying circumstances.

I go to work, I stay at the hospital with my child at night, and then I go back to work.

It was hard to keep the rest of the family going...we had to farm the kids out.

Every little thing seems to fall apart. Things don't work.

I gave away my career to take care of my child.

Good meals are gone...you do eat rubbish.

Looking after the farm was an important thing that had to be done. But it was a diversion that helped me keep going...it steadied myself...but I missed out on being with my child in the hospital.

Looking back now I should have quit my job. It was a bad mistake to try to keep on with my job. Going to work and trying to be at the hospital for treatments was an overload.

Emotional stress includes parents' strong feelings of pain and terror often associated with the diagnosis and treatment of a life-threatening disease such as cancer in children, the fear of relapse and death or disfigurement, and the ups and downs of uncertain outcomes.

Fathers have to be the tough guy, but I couldn't take it. For two years I just cried.

I get close to saying I'm out of here, I can't take it anymore, but that's not fair to my other girls because they can't escape.

It was hard for me that he was so weak and in pain. I had to carry him everywhere. I am afraid every time he's not feeling well.

Once they couldn't find a bone marrow match I knew we could only wait for death.

Never felt so helpless because there was nothing that could be done. I feel guilty about whether I did everything possible. My dying daughter said, 'Don't worry, its going to be alright.' It felt like she'd been here before and knew the way.

In some ways I'm better off now because our daughter's gone. I don't have to wait and watch any longer.

The constant threat of death was always looming in my mind and an overwhelming fear that my son would be gone and I would never see him again. How could I possibly cope since everyone figured that, or at least expected that, I would be made of steel and would support us all.

For some fathers the emotional pain centered around their lost dreams for their children, a theme echoed in the research conducted by Van Dongen-Melman et al. (1995).

My daughter is now in a wheelchair whereas she used to walk.

It is difficult to see him be fat and non-athletic. I had to refocus from what I wanted him to be and what I found interesting to enjoy more of what my son is and enjoys.

Every day I see what we lost, we have a child who is far from perfect.

I worry about how I am going to deal with this damaged child as an adult – he will forever be dependent upon us.

And guilt and anger often surfaced as a result.

I resent the hospital staff for not saving her life.

I am a nurse and I felt guilty that I didn't pick up on the diagnosis earlier.

I was ready to punch some of the nurses in the head because they were so stupid.

Interpersonal or social stress involves fathers' relationships with other people – in the family, in the workplace, and in friendship or acquaintance circles.

My other two boys have had no visible reaction and I don't know how to talk with them about feelings.

My wife could not talk about it, could not express herself, and that shut out a part of me.

My wife left me and my child.

My father broke down and wouldn't accept the reality. Friends deserted us also, and that hurt.

People we expected to support us didn't. And some we didn't expect to did.

Some of our friends were very understanding, others were not. I remember telling one person that my son's chances of survival would be 70-80 percent over the next five years. He replied, 'That's not bad, think of getting 75% on an exam, that's pretty good.' I replied, 'You don't die from an exam. Think of it as someone playing Russian Roulette with your son. With a gun that holds 10 bullets, with 2 or 3 bullets in the revolver. This gun is following your son around and it may go off in the next 5 years.' That thought is pretty nerve wracking.

Existential or spiritual stress concerns the ways in which childhood cancer challenged peoples' sense of the normal order of things - both material and spiritual - and the ways fathers tried to "make sense" out of this experience, how they had to re-think their lives and careers, and how they connected with their religious or spiritual beliefs and commitments.

It was a wake up call... 'Stop being a workaholic.'

I have a lot of faith that the Lord has healed him to this point. But I'm human - I worry.

I don't stress anything anymore. What happens happens – work, finances – I'd rather enjoy my child than worry about finances. I spend more time with the family and less time off by myself.

I have changed my philosophy of life. I take every friday off to be with my son - every day with him is a celebration. I've sold my businesses and have cut back to spend more time with my family.

I now sincerely thank people for praying for us.

#### How are these issues specifically difficult for men?

These kinds of stresses and challenges have been reported by women as well as by men, by mothers as well as by fathers. But some of these issues take a different shape and have a different impact for men, because of the things men learned (or did not learn) to be and do as they grew up and thus the differential impact certain events have on them and the different coping styles they have learned and prefer. The differences are especially profound and noticeable in the areas of emotional, practical and social/interpersonal stress.

Emotionally, it often is difficult for men to be in touch with their feelings, especially the "soft and caring" feelings. Men have been trained and are expected to control their emotions (Cook, 1984), to be stoic, to be "strong", to "keep a stiff upper lip"

and to be the “rock on which the family rests. The notion of being a “rock” is a common metaphor in men’s lives. In one group session of fathers a man said, ‘My wife says I do not share my feelings much with her, but I feel like the rest of the family needs me to be strong and that I am the rock on which the others rest.’ At this point another father remarked, ‘You’re going to find out that you’re a pretty mushy rock, after all.’ Other fathers indicated similar self-descriptions and similar understandings of the meaning of ‘being strong’ in this situation in the following terms:

I put my ‘stuff’ in a box and put the box on my shoulders. Then I’m okay until my legs buckle.  
I have to be strong.  
My wife takes us to a psychologist and a social worker but it is hard for me to let my feelings out. What does a social worker know anyway?

Other investigators report a similar phenomenon: Kupst et al., (1984) notes that a common coping mode for fathers of children with cancer was “not talking about the problem” and Fife (1987, drawing from a study by Powazek) reports that “The primary difficulties indicated for fathers were a lack of participation in the treatment process, and an unwillingness to openly discuss the illness and related problems (p. 159).” As several women reported about their husbands:

I can’t really tell you what he went through because I’m sure it was much too painful for him to discuss.  
My husband wasn’t speaking to me. At the time he didn’t talk with me for three months. He still doesn’t want to talk about anything related to illness.  
He still is not a talker. He doesn’t share his emotions readily. My daughter and I both felt that he walled himself off emotionally to protect himself. This was the way he coped, he walled himself off.  
He didn’t really say very much about it. He really didn’t want to talk about it or deal with it; he kept it a whole lot more quiet, where I’m totally different. I had to read everything I could find on it and write down the blood counts...I thought at least with knowledge I had an edge on it.

One result of these men’s “strong and silent” style is that they often denied, ignored, covered up or failed to express feelings of sadness, pain, and weakness or vulnerability. They not only failed to discover or signal their own needs for help, they often were hard-pressed to provide emotional support to others, to their wives and children. As several women reported:



He doesn't even want to discuss the after-effects of cancer, still to this day...he cannot deal with any of it. I mean I can't have a conversation with him about it. Oh, it gets really aggravating.

I think a lot of the feelings that I have towards him now are because of the way he treated me during that time that I was spending so much time with our son and he alienated himself from it. And I have a little resentment because, like, I had to go through it all by myself.

He was a basket case and our life was so difficult. I wanted a husband. He wasn't capable of giving me anything.

Another result of men not expressing their feelings was that some wives saw this as a lack of support for them or a lack of caring about the ill child.

Maybe my wife feels like I've grown further apart because I locked myself in.

These are things I just don't talk about. If you had tried to do this interview a year ago I couldn't have talked to you. I know this upsets my wife but my way of not going crazy is not to think or talk about it.

And as one wife reported:

My husband's response in terms of his coping style is to intellectualize an experience. My coping style is to go right to the feelings. And of course these two styles are diametrically opposed. We were not aware at the time that I did not feel support from him. I felt very isolated because he didn't seem to be experiencing anything. Like he didn't seem worried or wasn't feeling what I was feeling or wasn't understanding what I was feeling. And I think that made me angry at some level.

Hughes & Lieberman (1990) report how this clash of gendered styles was particularly problematic in one family: "Mother very much wanted to share her feelings, but her extreme need to express her anxieties was countered by her husband's equally extreme need to avoid doing so. Each partner feels hurt by the other's apparent insensitivity and this led to an increasing distance and anger in the marriage (p. 62)."

Finally, when emotional control was overwhelmed by the experience of parenting a child with cancer, when defenses were breached, some men were hit very hard! First a wife, and then a husband, reflect this experience.

He's not very big on letting his feelings show. But one night when he came back from the hospital, I've never seen him like that, never had, never had in 21 years. He was sobbing and sobbing...

I thought I was coping well. Then it hit me like a ton of bricks when my younger son got to the age when my son who had cancer died.

With regard to practical stresses, it often is hard for men to learn the new skills and to commit themselves to take on the new chores or divisions of household labor that may be necessitated by the crisis. As one man reflected on this issue:

Whenever there's trouble I have to hand the responsibility to someone else. I get so paralyzed with fear there's nothing I can do.

In fulfilling the other side of the "gender construction", women who are the child's and household's primary caretaker may be prepared to "do it all", to take on all the tasks associated with caring for the ill child and supporting the rest of the family (Cook, 1984). As Friedman et al. report, "mothers found the nursing role (participation in overall care of the child) consistent with their past experiences and self-image (1977, p. 362)." Clearly, many – but not all - fathers were not prepared to take on this role and were quite prepared for their wives to do so. Family history, as well as role socialization and expectations, may have placed many mothers in this role from the outset of family life, but some women (and their husbands and children) resisted any initiatives (their own and others') to alter these dynamics. Then, even those fathers who may have wished to take on new family responsibilities, to learn new skills, to share more deeply in caring for their ill child, may not have had access to such opportunity. Several fathers reflected on this issue as follows:

My father said, 'Why are you -- as a man -- spending time in the hospital.

Shouldn't you be back at work?'

I had to fight to stay with the baby in the hospital - my wife wouldn't let me.

One couple evidently succeeded in making the role transition.

My wife and I have reversed the traditional roles. I stay at home with the kids while she works.

And some mothers and fathers "did it together", as two mothers reported:

I guess we just, kind of, we'd cry on each other's shoulders...he just, he just helped, he's a good helper anyway.

We were just so supportive of each other, there were times when I was the strong person and I was there handling everything and then I had reached my limit and I was falling apart. And he would step in and take over for a while.

Fathers' primary roles as providers and protectors of the family left many men severely challenged if they did not have sufficient insurance or extra funds to pay for the child's medical or related expenses. In addition, fathers' careers were likely to be affected quite differently by the need to care for an ill child than were mothers' careers. Certainly mothers who stopped (or cut back) working to care for an ill child were vulnerable to loss of job or loss of their prospects for advancement. But many employers "expected" mothers to reduce work if their children are ill, and (some) were prepared to make accommodations; the same was not true as often for fathers. Despite provisions of the Family Medical Leave Act in the United States, this situation still affects many families' economic futures. And the pressure to continue to work, to maintain one's job/career position, and to help "provide" for the family, also often was costly in terms of family dynamics. As several fathers reflected:

I realize now how lucky I was to get three months off with full pay. I don't know how I would have managed without that.

Everything was done during the day when my wife was there and I had to be at work.

I had to work and couldn't be with her at the hospital. She'd spend many nights at the hospital while I was working overtime. When she did come home she'd be cranky and all she'd talk about was our daughter.

I have guilt that I let my wife do so much of the caretaking. I stayed the 'provider.'

Cook notes the ways in which fathers' often reported trying to balance "... two compelling sets of obligations: those relating to their jobs and those connected with home and family. Particularly when their child was hospitalized... (1984, p. 82)." One father who often was present at the hospital discussed having seen this dilemma in operation:

I have seen it with one of my child's roommates in the hospital. One kid's parents live three hours away, and the mother comes up for the week, and the father only shows up, because of his job and the other kids, maybe Saturday night. That must be difficult to deal with, both from the mother's point of view because she's not home with the other kids, and from the father's point of view because

he almost never sees his sick child. I feel bad for those fathers and for the child who doesn't get to see her father.

And in one of the relatively rare instances in the literature that reports fathers' experiences, Tucker (1982, p. 204) notes: "At work (he) had been preoccupied and depressed, and it was only the fear of losing his job that had forced him out of his daze and back to work. He could not even take a day off to rest his nerves." In those cases where employers do not permit men to take medical (or other) leave to care for our child they may be faced with a job loss, change or move in the midst of our child's illness. Indeed, Tiller et al. report that some "fathers showed a marked (temporary) decrease in work performance, usually associated with a moderate depression...(and) lowered their incomes (1977, p. 178)."

Of course, it also was true that some men "used" the demands of their work lives as opportunities to escape from the emotionally or practically challenging situations of home and hospital life. As two wives reported:

He became absolutely manic about work. He got very involved in work and had to travel a lot.

He was supportive in a distant way. He would stay away from home more and more because I am sure it was easier not to be home.

Even more serious "escapes" are reported by Obetz et al. (1980), who note that some fathers who were severely threatened by their child's illness engaged in excessive drinking and frequently absented themselves from hospital and home. As two wives reported:

I remember that my husband was just totally consumed and I say this with understanding, but it didn't help me. He was totally consumed with himself. He was out there drinking coffee and smoking cigarettes.

He began to drink more during that period of treatment. He masked it a lot. I think it was harder for him because it was killing him and so he drank more and that's how he dealt with it.

In the interpersonal arena, one result of fathers' inability or unwillingness to express their needs for help and support was that they did not receive what they

needed from others (e.g., Peck, 1979). Then some felt “left out” or “uncared for” by their wives and friends. As one wife reported about her husband:

I had a lot of support. I had an outlet and a release because the doctor sent over other parents and it helped to talk these things over. But my husband was coping differently. He did not feel comfortable talking things over with other parents. And so it was real private for him.

In addition, single fathers, stepfathers, or fathers separated from their children and former wives faced both the problems of coping alone and of figuring out how to be helpful to others.

### The role of the broader culture

It is not only or simply men’s own upbringing that sets this stage. The broader western culture frames men’s lives (and women’s) in ways that make the situation of parenting an ill child distinctively traumatic for men. This plays out in a variety of ways. Women are socialized to be the primary caretakers of children when they become parents and are more likely to ask for and receive emotional support from family and friends during their child’s illness. This is a result of cultural expectations that women need, wish for, and are accepting of such support, and that men are not as needy and not as desirous of such assistance. Especially when men do not express their needs, and especially when other men are unable to deliver such support, many fathers feel left out, uncared for, and lost. Male friends may not know how to respond, and fathers’ own fathers, sometimes present and able to be of assistance, and sometimes distant and themselves unexpressive, may be the models for their own conscious or unconscious emotional styles. As some fathers commented about male help – and non-help:

When I went to my father for help I ended up spending more time and energy taking care of him than his being helpful to me. My father was not able to reach out and feel me or touch me in any significant emotional way.  
My friends didn’t want to be around an emotional wimp like me.  
My best buddy said, ‘Goodbye’. Then he went away and cried because he couldn’t handle it. There seemed to be little concern for the father at times. People would constantly ask me how my son was doing, which was understandable, but then shift to, ‘How’s your wife taking all this?’ I don’t ever recall anyone ever asking

me, 'How are you taking this?' I guess they just assumed I would be okay. I felt very alone.

Only a couple of people asked me how I was doing. I think my wife experienced that a lot with her friends, but I only had a couple of friends who asked me how I was doing. If I could wish for anything it would have been more of that.

The difficulty of friends' disappearance, or of their not thinking of helping, or of their not knowing how to help, is reciprocated by the difficulty some friends expressed in being able to reach or help the distressed father (Chesler & Barbarin, 1984). For instance, as some friends reported:

As far as giving him support, I don't think anybody could at that point. He was in the position of having to be the rock. I felt bad for him because he couldn't draw that much support from anyone, because everyone was drawing support from him. We were there for him too, but I'm not sure I helped him emotionally that much.

I tried to indicate to him that he mattered and that he wasn't expected to be quiet, strong, and long-suffering.

He didn't seem to need us the way his wife did. He had his work and we couldn't help with that.

Inside the intimate family system as well, mothers generally report receiving less support from their spouses than fathers report getting from their spouses. In a study of parents of children with cancer in 55 families, Chesler & Barbarin (1986) indicate that 92% of men reported that their spouses were "very helpful" to them during their child's illness, contrasted with only 59% of women making such a report. As a result, some mothers ended up taking care of their husbands' emotional crises as well as their own and their children's...and resenting the overload. As two wives reported:

Once the initial shock was over and I'd gotten pretty good and taking care of our son, of handling everything, it sort of all fell on me - the appointments, the treatments, the doctors. My husband really went into heavy denial.

The difference in his life wasn't as drastic. My life changed totally, taking care of our child and making long trips back and forth to the hospital. And he still went off to work and came home and he had support. And yes, he had a child that didn't feel well, and had no hair, and things like that, but only little things changed for him.

Thus, men and women's socially constructed gender roles, in and out of the family, create conflicting needs and expectations. As Barbarin, Hughes and Chesler report in

their study of 32 couples, "For wives, spouse support is associated with their husbands' participation in the care of the ill children....Wives' favorable perceptions of marital quality also are related to their husbands' active involvement in the children's medical care and to their husbands' seeking information about the illness and treatment (1984, p. 478)." In contrast, "...availability of the wife at home appears to be of critical importance for the husband's experience of marital support (p. 479)."

Another stage on which these issues play out is the medical arena. Mothers usually become the primary link between the family and the medical care system; Cook (1984) notes that they assume the major nursing role and are more steeped in the culture of children's illness. Many fathers, then, felt left out of the direct chain of information. When fathers received medical information about their child through their wives, they received second-hand information. Some who questioned their partner came to resent "the messenger" as much as the message. In addition, the culture of the medical system plays a role in reinforcing some of these gendered dynamics. In most instances pediatric oncology staffs are more accustomed to dealing with and relating with mothers than with fathers. The hospital wards (and social services, schools and other childcare institutions) often are dominated by females, and pediatric staffs are among the most female-represented specialties in all of medicine. Staffs thus may be more comfortable dealing with female family members, and may resist male intrusiveness, assertiveness and assume that fathers are less competent as caretakers of ill children. As McKeever notes, "Often fathers are ignored or assigned peripheral roles by health professionals (1981, p. 124);" they have less contact with health professionals and report receiving less support from them. Several fathers commented on these issues as follows:

The father gets a lot of abuse from the nurses and hospital staff, especially during the night shifts and when the shifts change.

When our baby threw up the nurses would clean it up when I was there, but they didn't do that when my wife was there...she had to do it.

The help the staff offered, even their talk, was all geared toward the mom. None of the professionals there could relate to me.

The physicians don't seem to mind when my wife asks them questions. Maybe they feel more comfortable with her because she is the one that goes in most

of the time with the chemotherapy or what have you. And maybe they feel more comfortable because they don't think my wife will be as aggressive with them as me and other fathers might be.

Some mothers confirmed the operation of this dynamic:

I made a lot of friends at the hospital and got to know the social workers and people. So I did a lot of talking with them.

I think my husband was jealous of the whole hospital scene thing. I think he felt neglected through the whole thing....like an outsider in the hospital.

### Changing men...changing lives.

The literature on childhood cancer increasingly reports that this can be a transformative experience for everyone involved – for mothers, fathers, survivors and siblings - in potentially positive as well as negative ways. Indeed, some men reported that they had changed in fundamental ways as a result of their experience. Some changed because of the help they got, or because they came to new understandings of their wives or children, or because of the basically transformative experience of dealing with a child with cancer.

It is not an experience I would trade. I would not have asked for it but I have grown in my relation to my wife, to my child, and to God.

At the end of my child's life I understood the meaning of life more.

To this day I am deeply touched by my son's concern for me during that period. It was him who was sick and had to endure all of the treatments and the pain and yet when his mother and he were told that he was going to die his concern was, 'How are we going to tell dad?' Though I am not a religious person I feel strength knowing that he had a lot of faith in God and after they finally did 'tell dad', he said to me, 'Don't worry dad, we'll all be together in heaven someday.' I await the day to be with him again just like he promised, something that I now hold very precious.

I've become stronger out of it. I try to enjoy life and not make plans for the future...no more working all hours.

Like everything else in your life you work it through, because if you are strong enough to handle the disease, you're strong enough to handle anything. So we just went on with our life and just kept digging into everything. I am back to work and doing everything I was before. We can handle anything. If you are forced into it you obviously don't choose to do it, but it is amazing how strong we are.

I think that this has opened me up. I come from a background where you always held things in, especially the males on my side of the family, and you never complained. You just had to hang in there and do what you've got to do. And I think this broke down that barrier and I've been able to express things. Yeah, I



think I've been able to open myself out, break down those barriers and be a lot more expressive.

Other aspects of men's changing career and family orientations and behaviors were presented earlier.

Several of the men interviewed indicated that their change had been facilitated by access to psychological counselling.

I had to go through some counselling because all of this boiled up a year later. It all really came to a front and I had to have a little bit of help to work all that out. Counselling was a lot of talking about who I was, where I came from as far as holding my emotions in, holding my things, holding my feelings in, being more passive with information...

And as one wife reported, counselling with an added friendly push might be even more effective.

He was the type when something bothered him he wouldn't talk about it. He would just keep it to himself and one day, after the counselor told us this thing would either make us or break us, I looked at him and said, 'I will not let this break up our marriage.' And ever since that time on the freeway we have been very, very close.

Prior research indicates that one way or another, most fathers of children with cancer indicate that they figured out ways to improve their lives as a result of this experience (Chesler & Barbarin, 1986). It is not only most fathers who report that their lives changed for the better or that they have become "stronger;" most mothers report a similar phenomenon (Chesler & Barbarin, 1986; van Dongel-Melman, 1995). And despite the evidence of family tension and strain, most parents report that their marriages were stronger and that their families were now closer together as a result of the ways they coped with this experience (Chesler & Barbarin, 1986). Both mothers and fathers, in relatively equal degree, indicated increased satisfaction with family life: 54% reported feeling "more positive toward their spouse" and 60% stated that their family was closer together now (Barbarin, Hughes & Chesler, 1984, p. 475).

Despite these encouraging reports, it is clear that this is not a universal reaction! As one father said, undoubtedly reflecting the experience of others:

This business about 'coming out of it stronger' is a bit of rubbish.

The value of a fathers' workshop - or support group.

The "fathers only" workshops that have become popular (or at least the ones the senior author has been associated with) can best be conceived as "one-shot support groups". They generally accommodated 15-25 men, and have been closed to mothers and other sightseers. Some of these fathers have had children still in treatment, some of their children were off-treatment and some of their children died from cancer. Some of them had met each other before, in the clinic or hospital setting, or in a local self-help or support group. The men reported that they came to these workshops for a variety of reasons: some to share their feelings with others, some to ask questions of others like themselves, some to ask others to pray for them and their children, some out of curiosity, and some because their wives "insisted" on it. In every case, these sessions were heartfelt and intense, with deep sharing of feelings -- with laughter and tears -- with hugs and handshakes. In no instance was it easy to end the session after the 1 and ½ or 2 hour time limit.

Certainly the men who attended these workshops, and who so openly shared their experiences and feelings, were not "representative" of all fathers of children with cancer. They were a self-selected group, and the very fact that they came to public sessions of this sort distinguishes them from the many fathers who did not or would not do so. But each father carries every father within him, and they knew quite well the dominant roles they were expected to play, as well as the costs and benefits of diverging from dominant gender constructions. The reports of these workshop attendees, and the other men quoted in this paper, clearly outline the major struggles faced in some fashion and degree by all fathers of children with cancer.

To the extent that recognizing, acknowledging and dealing with these issues -- especially these feelings -- is difficult for men, it may be easier for them to discuss and explore them with other men, specifically with other fathers of children with cancer. It may be easier in this context than with their own wives, who are so intimately connected to their lives, or with friends who are only peripherally connected with the

realities of childhood cancer. And the recognition of the commonality of these issues also may ease each individual's sense of pain and loneliness. As several men indicated:

Every man in this room knows how I feel, but other men really don't. I was that way, ignorant and distant, before my son had cancer. You other bereaved fathers were after all the only ones who did understand and who could truly say to me, 'I know how YOU feel.' Just being able to break down and cry and not be held accountable was in itself cleansing. Oh the joys of being a male -- right?  
We may never again be anywhere near so many other men who are struggling or who have struggled with the same issues. Let us keep finding each other and meeting again.

And in the context of a supportive workshop setting, some men were able to ask for specific kinds of assistance.

I want to know where the rest of you guys get help. My wife was with our child in the hospital all the time. She was surrounded by people who are helping her all the time. Where do I go for help?  
I think if I had known someone in my position one of the things I would have liked to ask him was how are you coping with it.  
This time next week I expect to bury my daughter -- please pray for her...and for me.

Immediately upon hearing this last comment three men rose from their seats and touched or embraced the speaker, asked for his phone number, and promised to pray for him and his daughter and to stay in touch. If these expressions of feeling and need, and the reactions and offers of assistance from other fathers, can happen in the course of a single two-hour session among relative strangers, what miracles might be wrought in the context of an ongoing system of support?

There are some cautionary tales regarding the formation and conduct of all-male support groups or workshops. Given the larger history of what has happened when men met apart from women (and often bonded together and made decisions that had negative implications for women's lives), we may be legitimately concerned about the social implications of such events. How can we ensure they will be productive of openness and positive change rather than leading to a "circling of the wagons"? In turn,

how can women be helped to be comfortable with the utility of some gender-separate sessions? Moreover, efforts to share intimate information with other men about one's spousal and familial situation and tensions (regarding emotional interdependency, chores, sexuality, etc.) are fraught with delicacy and dilemmas of spousal loyalty. This challenge usually is more than counterbalanced by: (1) the relief encountered when men hear that other men have wrestled with the same issues; and (2) the feeling that these issues could not and would not have been shared (if at all) in any other setting outside of the immediate family. Finally, groundrules have to be set and kept regarding confidentiality of these discussions: no one wishes to take the risk that what they say in these settings will be shared in ways that make them or their wives and children more vulnerable than they already are.

#### How do/can we help fathers?

One natural extension of the workshop design is the formation of an ongoing fathers' support group. This occurred for some fathers in the context of local Candlelighters' (self-help and support group) meetings.

My suggestion for keeping up the conversation we had at the workshop is to have meetings every few months to get together and take it further.

All the Candlelighter camps, conventions and parties were very rewarding to go to.

To be able to talk to a lot of other people, especially men, who had dealt with childhood cancer made all of us a bit stronger. Every time I talked to someone about it, it seemed a little easier to cope with.

My advice is, don't be without a support group at any time, that's number one...

And as one woman said:

Maybe my husband would have done better if he had gone to those support groups and I had not attended with him. Maybe he would have opened up and fared better.

Surely some such groups exist and some followup occurs. Unfortunately, the evidence seems to be that relatively few men participate actively and regularly in local self-help and support groups meetings, and that separate support groups for fathers of children with cancer are even rarer (Chesler & Chesney, 1995).

The agenda for helping and supporting fathers seems to include at least six foci: (1) attention to the value of promoting open discussion, among men and between family members, of fathers' (and others') feelings about the ill child, other children, the wife's coping style; (2) open discussion within the family of the ways in which various coping styles and support patterns do or do not meet each family member's needs; (3) discussion of the impact of the illness on fathers' sense of self, emotions, ability to continue to work and "provide" for the family, visions of the future, and willingness to be engaged in the treatment process; (4) assistance to fathers' willingness and ability to ask for help, and a focus on the places and services/resources that may be helpful to them; (5) discussion of what fathers' have "learned" from their experience with an ill child, and resultant family and role dynamics, and how they have changed (for better or worse) through this situation; (6) opportunities to share any and all of the above with other fathers of children with cancer, hopefully breaking down the walls of loneliness and individuality that separate men from one another and create the feeling that everyone is fighting this battle alone and without mentors or guides.

Some medical centers have begun to experiment with ways of responding to these needs of fathers (and mothers) of children with cancer. In one especially interesting innovation, Kazak et al. (1998) report a program that brings together several families, and has fathers, mothers, survivors, and siblings meet for a period of time separately and then together. The focus of conversation is how the experience of childhood cancer has affected each family member. This approach appears to combine the best aspects of two strategies; separate time for each party to meet with others like themselves and together time for entire families to discuss openly their concerns with and for one another.

It is clear that men need more such opportunities, short-term and long-term, for fathers separately and for entire families together, inside and outside the formal health care system, for unburdening, surfacing and sharing the feelings and practical coping strategies they have developed for dealing with the stresses and challenges of childhood cancer.

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