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Oncologists’ Protocol and Coping Strategies in Dealing with Patient Loss

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Abstract

To identify what protocol and coping strategies oncologists turn to cope with patient loss, we interviewed 20 oncologists at three hospitals. Using the grounded theory method, findings revealed that their protocol may include: meeting with families, participating in bereavement rituals, making a phone call, or sending a condolence card. Coping strategies included: social support, activity-oriented coping, turning to faith, compartmentalization and withdrawing from patients and families. We conclude by offering implications from this research on how to address oncologists’ grief over patient loss in institutional settings in order to improve bereavement care for families and enhance oncologists’ quality of life.

KEYWORDS: Oncologists; Grief; Patient Loss; Coping Strategies; Protocol on Patient Loss; Grounded Theory.
INTRODUCTION

There is research to suggest that caring for critically ill and terminal patients can generate grief reactions in health care professionals (HCPs) (Feldstein & Gemma, 1995; Redinbaugh, Schuerger, Weiss, Bruisky, & Arnold, 2001; Shanafelt, Adjei, & Meyskens, 2003). HCP’s report feeling grief over the deaths of patients with whom they felt close, who failed to be cured by standard treatment interventions, who were younger patients, and who lacked dignity because of multiple failed resuscitation efforts (Redinbaugh et al., 2001; Shanafelt et al., 2003). Moreover, some research has found that HCP’s consider grieving over patients unprofessional, shameful, and/or a failure (Meier, Back & Morrison, 2001).

Unmanaged negative emotion including grief in HCPs working in oncology settings can lead to stress, burnout, and alcohol and substance addiction (Shanafelt et al., 2005); high turn-over (Feldstein & Gemma, 1995); professional loneliness, loss of professional sense of meaning and mission, cynicism, helplessness, hopelessness, and a sense of frustration (Meier et al., 2001); and, clinical psychiatric distress symptoms such as anxiety, insomnia, moodiness, and difficulty concentrating (Meier et al., 2001).

Despite the evidence that grief over patient loss is a part of the oncology setting, to our knowledge there are no qualitative research studies examining how oncologists deal with the grief of continually losing patients including what protocol and coping strategies they employ to deal with loss. The purpose of this analysis, which was part of a larger study examining oncologists’ experiences of patient loss, were to explore and indentify what
protocol (if any), exists on dealing with patient loss in hospital settings, and what coping strategies oncologists turn to cope with their grief over patient loss.

METHOD

Participants

We used a grounded theory approach in our study design (Glaser & Strauss, 1967). We recruited and interviewed 20 oncologists between November 2010 and July 2011 from three adult Canadian oncology centers in Ontario that varied in size from a small (27 oncologists); medium (32 oncologists); and large center (80 oncologists). Three groups of oncologists who were at different stages of their career trajectory (e.g., residents, junior, and senior oncologists) and who varied in their sub-specialties, gender, and ethnicities were interviewed. Aside from 1 radiation oncologist and 1 palliative care specialist working in the oncology setting, the participants were all medical oncologists who ranged in age from 30 - 65 with average being 47 years old. Most (16, 80%) were married and had children (14, 70%). Years of practice ranged from 1.5 years in the case of residents, to 31 years practicing oncology in the case of senior physicians with the average being 13 years. The number of patients seen monthly ranged from 44 - 360 with the average patient load being 176 a month. Number of patient deaths per month ranged from 1-10, with the average being 4 per month. Exclusion criteria were the inability to speak English and never having had a patient die in their care.

Procedure
After obtaining approvals from the Research Ethics Board at each participating healthcare center, the oncologist co-investigators (RT, MK, & PM) emailed information about the study to obtain consent to be contacted about the study. If the oncologist agreed to be contacted or to participate, LG, the principal investigator, who is a psychologist and who did not work with, or know any of the potential participants, followed-up with a telephone call to describe the study and schedule an interview. In all, 15 oncologists responded to the first email recruitment and all agreed to be interviewed. After conducting and analyzing 15 interviews, we targeted participants who were not represented in the sample. An additional five oncologists responded to the second email and they were subsequently interviewed.

All interviews were conducted by LG, an experienced qualitative researcher. Each participant consented and agreed to being audio-recorded at the beginning of each interview. We used a semi-structured interview guide that was continually revised throughout the process of data collection and analysis in order to refine emerging themes. The questions encouraged oncologists to discuss their experiences in-depth (See Appendix A for a list of sample questions). Interviews took place in the oncologist’s office and lasted between 40 minutes to an hour and a half.

**Data Analysis**

Data collection and analysis took place concurrently and line-by-line coding was used. LG and a research assistant separately coded the first five transcripts, followed by several team discussions on the developing coding scheme to ensure consistency between coders.
and validity of the emerging findings. Analysis was inductive and involved line-by-line coding, with codes and categories emerging from participants’ stories. As the analysis continued, the descriptive codes were further distilled to capture the major themes and sub-themes emerging from the participants’ narratives. Constant comparison was used to examine relationships within and across codes and categories. LG memoed thoughts, reflections, and reactions extensively throughout the process of data collection and analysis, which later were incorporated into the write-up of the manuscript. Data collection stopped when the team determined that we had reached saturation and that no more new codes and themes were created. We used NVivo 8 computer software to organize, code and store the data.

Horizon Of Understanding

A horizon of understanding includes the researchers own implicit and explicit values that evolve from their cultural, historical, and geographical contexts and is often included in qualitative analysis reports (Rennie, 2000). In this analysis, the research team was comprised of one psychologist (LG) whose expertise is in grief and loss (See Granek, 2010 a;b), and three oncologists, one of whom is a palliative care specialist (PM). All members of the research team have an interest in the emotional well being of healthcare professionals and all the oncologists have had experiences with patient loss. The co-investigators informed the data collection and analysis process by drawing on both their clinical and personal experiences as oncologists and as professionals who train other oncologists.
RESULTS

Two findings emerged pertaining to what oncologists *do* when patients die. The first category focuses on protocol around patient loss or what oncologists *do in the day to day* in responding to losses in their workplace context. The second category has to do with how they *cope* with these losses. We report on the resources oncologists turned to in order to manage their grief, and what coping strategies they utilized in tending to their losses. In Table 1 we summarize our findings in a chart form outlining the major categories, themes and sub-themes.

*Protocol*

Since death and loss are a constant part of the oncology setting, we had assumed that there would be a written protocol on how to deal with patient loss. Surprisingly, however, there were no explicit guidelines on what do when a patient die at all three hospital sites and physicians were largely left to decide on their own what to do. One oncologist remarked, “There has never been any kind of given instructions, and I never, quite honestly, asked my colleagues.” Many oncologists expressed curiosity at what other oncologists were doing, and had heard rumors that some attend funerals or send cards, but there was no formal conversation about what anyone did, and none knew who they might contact to find out about protocol. Moreover, what oncologists do after a patient dies was arbitrary. One oncologist noted: “I don’t have a protocol, I’d say it’s pretty ad hoc.” Another noted:
“I think some people do send condolence cards, I think others don’t do anything….I don’t think it’s expected. Nobody talks about it. To be frank, I don’t think anybody kind of addresses that kind of stuff.”

If oncologists did reach out the family in some capacity it fell under the following themes:

Attending Bereavement Rituals such as Funerals, Shivas or Wakes: Some oncologists reported attending funerals or other types of visitations such as a shiva or a wake, but this was rare, and often happened once or twice early in their careers and never again because they felt that it was too emotionally draining. One oncologist noted:

“I don't make it a practice to go to funerals just because I think maintaining that professional boundary. I have done it for two patients over the years, and I just found that I needed to kind of separate that side…I don't think emotionally that this is something that I can hold up to.”

Meeting or Speaking With the Family: Meeting or speaking with the family after a patient’s death was also arbitrary and rare. In a few instances, oncologists made an effort to reach out to families and invite them for a conversation after a patient had died. One oncologist explained, “I always leave an offer that if you have any questions later on, any member of the family, or you need to come and meet me, please do so.” Another oncologist noted that meeting with the family was an opportunity for closure for everyone including the physician. They explained:
“You’ve been with the family, it’s not just the patient… You’ve been with the family in a ridiculously intimate way …I think sometimes its closure for them as well. It’s definitely closure for you. I always think it’s usually more for the family, but then I end up feeling better just hearing something about this patient I didn’t know… that kind of feels better.”

Making a Phone Call: In some cases, oncologists followed up with a phone call to the bereaved family. Few oncologists reported doing this consistently. One oncologist remarked, “I think people just develop their own thing; I usually call every patient’s family who’s died at some point in time.” On the other hand, others remarked that making a phone call was fairly ad hoc, and usually extended towards family members they had felt particularly close to. An oncologist explained:

“I try [making phone calls], I must admit, it depends on how close I am to the family…. there are families that you’re just closer to than others…. I’m not consistent with it.”

Sending a Condolence Card: Some oncologists sent a condolence card to the bereaved family members, but this was also rare, and often the primary nurse took the lead on this practice. The issue of condolence cards was a ‘hot’ one for oncologists. Some spoke about how they wished they did this more consistently for every patient. Often times, the intention was to send a card in order to reach out to the family and to give them a chance to be in touch if they had any questions or for the purpose of closure, but this practice often fell by the wayside because of oncologist’s workload. In addition, oncologists had some ambivalence about whether sending a card was ‘the right thing to do’; some spoke
about wanting to know what the patient’s families desired on this matter. One oncologist explained that in their practice:

“I will often send condolence cards, unless I happen to watch them die or with the family. If I was actually there with the family, I won’t send the card after necessarily. Sometimes I’ll call, you know, depends on how close I was to the family, spouse or whatever.”

Coping Strategies

Given that there was no official protocol around what to do when patients die, we asked several questions about what physicians do to cope with continual loss. Coping strategies fell into three broad domains that included social support, activity-oriented coping, and other coping strategies.

Social Support

Drawing on social support to cope with patient loss meant turning to a spouse or a family member, a primary nurse, or other healthcare professional such as a colleague. In some instances, oncologists reported having no support and/or having a negative experience with colleagues in the past that led them to avoid using social support as a coping strategy. The main place oncologists turned to for social support was their spouse. In some cases, oncologists spoke about turning to another close relative. If the spouse or relative was a medical professional, oncologists reported that talking about grief was easier, however, many discussed the need to curb these types of conversations because they felt it “wasn’t fair” to burden the spouse or to take one’s work home even if was
affecting them. One oncologist explained, “It's just very cathartic to get it out… I think in being an objective voice and someone who kind of knows, and quietly listens, that's very helpful.” Colleague support mainly involved confiding in the primary nurse who had known the patient, and therefore, could empathize with and understand the loss. These conversations did not happen frequently, but when they did they were described as being short, informal, and arbitrary. For example, one oncologist noted:

“[Nurses] will get quite attached to patients. They're often the ones that are holding their hands, and doing all the very close things. So, sometimes just speaking with my nurse about the issues really helps as well because they know the patient and the family.”

Sometimes oncologists turned to other healthcare professionals to talk about difficult patient loss. This was, however, a rarity, and as with nurses, when it did happen, it was an informal, spontaneous, and short conversation. In those instances where oncologists did turn to another oncologist for support, it was someone they knew well. Talking to other colleagues was considered a vulnerability, even a potential liability, and therefore, was unusual unless it was a thoroughly trusted colleague. For example, an oncologist explained:

“There’s a little bit of a risk to [talking to colleagues]….I think you can feel comfortable sort of sharing your loss but often times there may be parts of that patient’s care or decisions that were made that people may not agree with and then there’s some associated guilt or blame and that’s where it becomes something that I’m sensitive to. Some staff I feel very comfortable talking very openly about and then some would take it as either a threat, or look at it very analytically and try to absolve themselves of any kind of responsibility for any of the decisions that were made. I think that’s part of it is from
the healthcare provider side, is the part that may promote the stigma about not talking about things so freely.”

On the other hand, another oncologist who was able to seek support from colleagues remarked:

“Luckily, I’ve got two really close oncologists who I discuss any sort of things that I have going on… it’s such a good release to talk about issues that have happened in your week.”

Many oncologists said they had no professional or personal resources to talk to about patient loss, or in some cases, that they had had a negative experience with colleagues in the past around this issue. When asked whether she spoke to colleagues or anyone else about a particularly difficult patient death, one oncologist responded “No. There’s no one to talk about it with.” Another noted that his colleagues do not want to discuss this issue. He explained:

“I've raised it [grief over patient loss] with our group... they're all focusing in on the medical-knowledge, content side of things, and say, “oh I don't know, that's kind of hokey, and you know, we're comfortable dealing with it on our own.””

A few oncologists described having a negative experience with colleagues speaking about patient loss to the degree that they had learned to keep their emotions to themselves at work. One senior oncologist told this story that had happened 30 years earlier: “I was a resident and I had 3 deaths in one night of young people. It was terrible. I went into the
on-call room and I started to cry, and it just turned out that the head of the department walked in and she said, “What’s wrong?” I said, well, 3 patients died and I feel bad. And she goes, “I don’t think you should be an oncologist, you clearly can’t cope with this”… I just learned that my grief is my thing and I don’t want to share it with anybody else. I don’t really care what other people think about it and I don’t want to be lectured about what to feel and what not to feel.”

Activity-Oriented Coping: The second set of coping strategies involved ‘doing’ something. These included turning to hobbies, spending time outdoors, spending time with family, taking vacations, and engaging in physical activity. For example, one oncologist noted: “I work 70-80 hours a week, I spend a lot of time doing research… When I’m doing research I never think about patients, and this probably gives me strength to deal with some of the atrocities I see as an oncologist.”

Another explained:
“I like exercise and outdoors and those sort of things. They help me relax and sort of see the world as sort of, it’s still a beautiful world, even though it’s full of death and illness, and nasty things.”

Other Coping: Other coping strategies in dealing with patient loss included turning to faith, compartmentalization or denial, and withdrawing from patients. Each is described in more detail below.
Many oncologists described turning to their faith or spirituality as a coping mechanism in dealing with continual patient loss. Some participants took comfort in the rituals of religion, and others spoke more generally about deriving faith in a power higher than themselves in coping with loss. One noted:

“I believe in God, I believe that there is a heaven for people to go to and that if they’re good people that there is another world for them… that certainly helps me realizing … that this is not the end for them.”

Another explained:

“In our religion, we believe that you shouldn’t be attached to things… In my personal philosophy, I think that everybody’s here for a certain period of time -- and I also think that physicians only have so much power. I don’t think I’m going to change the lives of, like completely change their lives every time. I realize that I’m just doing what I’m trained to do. If someone lives or dies it’s not really up to me, and I also think that from a religious point of view.”

In another paper on this topic, we report on ‘compartmentalization’ or the ability to separate one’s emotions in the workplace as an impact of continual patient loss (Granek, Tozer, Mazzotta, Ramjaum & Krzyzanowska, forthcoming). However, compartmentalization about patient loss was also reported as a coping strategy to deal with loss. For example, this oncologist noted: “I think, [compartmentalization] is a defense mechanism and it’s helped me cope from a day-to-day perspective in being able to go at home and isolate that side from me. So, it does help me in terms of the day to day
aspects.” As with compartmentalization, we report on withdrawing from patients in another paper in the context of the *impact physician grief has on patients* (Granek et al., forthcoming). We note here, however, that withdrawing from patients and their families as they approached death was also described as a survival strategy in protecting against being flooded with grief. Several oncologists remarked on this practice. For example, “That [distancing/withdrawing] probably helps with the whole thing. That actually helps with the entire grieving process because you almost let go before they die, and that’s probably why I don’t write letters to them because I don’t see them for the last 2-3 months of their life, and that’s probably a big buffer zone.”

Another explained:

“When patients are in a terminal phase of illness, we don’t have much to offer, so, let’s ask the palliative care doctors to see them. Psychologically, for me, that may be sort of a mechanism of avoidance. We don’t sort of feel the impact, right? Of seeing them die or seeing them not doing well.”

**DISCUSSION**

Our analysis revealed that oncologist’s had no official protocol on how to deal with patient loss and the subsequent grief that may emerge. Because there was no official protocol on an institutional level, oncologists turned to a number of ad-hoc strategies in both coping with the impact of loss and in dealing with families when their patients died. Some of present findings of this study are corroborated by the few empirical studies on oncologist’s protocol around patient loss. For example, one study that looked at Israeli
oncologists found that the majority rarely participated in bereavement rituals that involved any direct contact with families including funerals and shivas; 28% occasionally participated in rituals involving direct contact and 45% had some form of indirect contact such as sending a condolence letter. It is noteworthy that these oncologists reported making a telephone call “frequently” only 34% of the time (Corn et al., 2010.) Likewise, in another study looking at Canadian palliative care and oncology physicians, only 1/3 reported usually or always making a phone call, sending a condolence card, or attending a funeral following a patient’s death, and 36% reported never or rarely participating in any of these bereavement rituals (Chau et al., 2009). As with our research, these findings indicate that, across at least two different cultures, bereavement protocol for oncologists is arbitrary and rare. Further, although both of these studies revealed some of the practices in dealing with patient loss, neither addressed the institutional context in which these losses were happening.

One important implication is that providing institutional standardized protocol around how to approach families after a patient has died might help oncologists with this emotional work. For example, condolence cards can be made available in departments and time can be set aside each week for making patient family phone calls or having patient family meetings. Many of the present oncologists intended to send a card and/or meet with the family, but often did not follow through because of other work demands or due to being unsure of what the families wanted. By setting aside protected time within the work week to address patient families who are grieving, oncologists may be more likely to engage in bereavement practices with families. This engagement, in turn, may
have a positive impact on both patients and oncologists. Bereaved families have reported dissatisfaction with physician communication when it comes to end of life issues including insensitivity, lack of empathy, and feeling uninformed about what had happened to their family member (Heller & Solomon, 2005). Moreover, families often feel abandoned by the health care system and by their physicians, particularly after their family member died (Back et al., 2009; Billings & Kolton, 1999). Grieving families (Main, 2000; Milberg, Olsson, Jakobsson & Friedrichsen, 2008) and physicians (Collins-Tracey et al., 2009; Redinbaugh et al., 2003) want follow up bereavement care and find it helpful. Implementing a standardized, but non-mandatory, protocol may help ensure that oncologists engage in these practices more consistently and in the process, improve quality of care for patients and their families and quality of life for physicians.

The research on how oncologists cope with their own grief over patient loss has rarely been addressed empirically. Research on physicians indicates that most used talking to others, exercise, and faith as coping strategies in dealing with their grief (Moores, Castle, Shaw, Stockton & Bennett, 2007), as well as turning to work or other activities (Redinbaugh, et al., 2003).

Our findings revealed that oncologists turn to spouses or family members for social support around this issue, but feel uncomfortable burdening their families with this suffering. However, oncologists see other healthcare professionals such as colleagues as unavailable, or too risky for such discussions. Moreover if oncologists were reprimanded in the past for being honest about their grief, they were less likely to be forthcoming with
their struggles around patient loss in the present. Past negative experiences with medical training impacted their current practices.

What these findings imply is that although grief interventions for oncologists such as physician support groups (Lyckholm, 2001), personal reflection about death, dying, and grieving (Shanafelt, 2005), and institutional programs such as bereavement groups for physicians (Lewis, 1999) have been reported as helpful, apprehension about turning to colleagues and speaking openly about patient loss may be a significant barrier. Anyone who develops such interventions should plan on addressing these concerns.

In terms of general coping strategies, turning to faith is another interesting point of entry into helping oncologists cope with their grief. Faith and spirituality is a place that oncologists seemed to draw strength from in helping them cope with loss. In one study of oncologists, for example, developing an approach or a philosophy to deal with dying patients was cited as the single most important strategy to enhance personal well-being (Shanefelt et al. 2005). In another study, medical personnel who had frequent daily spiritual experiences tended to have less physical, emotional and cognitive distress (Holland & Neimeyer, 2005). Nurturing religious and spiritual life in institutional settings can take the form of providing regular healthcare professional memorial services for oncology staff and/or Grand Rounds or other educational opportunities that teach on various religious, philosophical, or spiritual traditions when it comes to end of life and death.
There are limitations to this study. Although the purpose of qualitative research is to gain in-depth understanding of an experience rather than its breadth, our small sample size and the fact that oncologists volunteered to participate in this study may indicate a self-selection bias. Since protocol for and coping strategies in dealing with death in the oncology setting has not been researched extensively, further qualitative and quantitative studies are needed to assess the viability of interventions and the generalizability to all oncology settings.

ACKNOWLEDGMENTS

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Appendix A: Selected Questions from the Semi-Structured Interview Guide

- Have you ever had any of your patients die?
- On average how many deaths of patients do you deal with on a weekly basis? If not weekly, monthly, yearly?
- What happens when a patient dies in your practice in terms of protocol of dealing with the family?
- I want you to think now of one patient who died that was particularly difficult for you. Can you describe the patient to me. If you wish, you can tell me their name, their age, how long you knew them, what they were like, what they meant to you, etc. How did you feel when they died?
- How did you cope with the patient’s approaching death?
• Did you talk about the patient’s death with any of your colleagues?

If yes, who, and how did they react? Was it helpful?

If not, what do you wish they would have said instead?

If didn’t talk to colleague, why not?

• Did you talk about the patient’s death with your family and friends?

If yes, who, and how did they react? Was it helpful?

If not, what do you wish they would have said instead?

If didn’t talk to family or friends, why not?

• Did you have any professional resources you could turn to in order to deal with your grief? (i.e. Support groups for physicians, fact sheet about dealing with grief, nurses to help with psychosocial care etc.)

• What other resources do you turn to, if any, to help you cope with your grief over losing patients?

REFERENCES


### Table 1: Categories, Themes & Sub-Themes

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