Death talk and relief of death-related distress in patients with advanced cancer

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Death Talk and Relief of Death-related Distress in Patients with Advanced Cancer
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ABSTRACT

Objectives: The circumstances of advanced cancer heighten the need for affected individuals to communicate mortality-related concerns, although there may be obstacles to such communication. Managing Cancer and Living Meaningfully (CALM) is a supportive-expressive therapy designed to address such barriers and to facilitate communication of mortality-related concerns in patients and caregivers facing advanced disease. This study explores death-related distress in patients with advanced cancer and the perceived influence of CALM therapy on overcoming barriers to communication of this distress.

Methods: Semi-structured interviews were conducted with a subset of patients with advanced cancer (n=17) participating in a CALM phase III trial at a large urban regional cancer center. Interviews were transcribed and qualitative data was analyzed using thematic analysis.

Results: Death-related distress was experienced in terms of three key themes: diffuse and overwhelming fear, fear of uncertainty, and fear of suffering. The perceived barriers to communicating such distress were: reluctance of loved ones to discuss mortality-related issues and the participants’ own reluctance to discuss death-related concerns to protect their loved ones or themselves from distress. CALM therapists were perceived to facilitate discussions on dying and death in sessions and to support patients’ communication of death-related distress with health care providers and loved ones.

Conclusions: Advanced cancer patients perceive barriers to effective communication of death distress to be related to their own reluctance, as well as reluctance of their loved ones to address such fears. CALM therapy may help patients with advanced cancer to overcome obstacles to communication and to alleviate death-related distress.

Keywords: advanced cancer; death-related distress; terror management; psychosocial; qualitative research

BACKGROUND

Advanced cancer is associated with fears and challenges related to disease progression and symptom burden, dependency and disability, suffering, and worry about dying and death.[1,2] These undermine self-esteem and sense of meaning,[3,4] may disrupt personal relationships, and generate emotional distress. The psychological consequences of an advanced cancer diagnosis may include elevated suicide rates.[5] There is evidence to suggest that psychological distress may overshadow concerns over physical symptoms in terminally ill patients.[6]

Death-related distress is common in individuals with advanced cancer.[2,7] Terror management theory (TMT) [8] provides a useful framework for understanding how individuals cope with death-related fears. TMT suggests that the fear, or ‘terror’, invoked by heightened mortality salience [9] is modulated by three protective psychological factors: the sense of meaning, self-esteem, and attachment security.[10] Although TMT has primarily been studied in healthy individuals, these factors are relevant for patients
with advanced cancer who may be preoccupied with existential fears as the threat of mortality becomes highly salient.[11,12]

Attachment security is the least empirically supported pillar of TMT. This construct refers to the internalized expectations of receiving, deserving, and making flexible use of emotional support.[10] An important component of attachment security is that the communication of distress to a supportive figure can help alleviate distress.[13] This suggests that communication of death-related distress in the context of a supportive relationship could help to ameliorate such anxiety.

In the context of advanced disease, heightening of attachment needs due to increased mortality salience may disrupt relationships in which there has been a longstanding equilibrium, causing distress in both patients and their caregivers.[14] In fact, caregivers may report greater distress than cancer patients themselves.[15] Patients with high levels of death anxiety may benefit from support, but the overwhelming nature of their distress may hinder open discussion about the end-of-life and advanced care planning with their loved ones.[16] A therapeutic intervention to relieve distress in one or both partners, and to facilitate emotional communication within this relational system [14] may therefore be valuable.

The CALM Intervention
Managing Cancer and Living Meaningfully (CALM) is a brief semi-structured psychotherapy that is intended to support attachment security and to facilitate communication between patients facing advanced disease and their caregivers. CALM is optimally delivered in 3-6 sessions over a six-month period. Primary caregivers are invited to attend sessions when this is desired by the patient.[4] The individual and couple-based nature of CALM therapy allows for tailoring of the timing and content of the intervention to accommodate the unique needs of those facing metastatic cancer and their caregivers. Unlike Dignity Therapy, which has shown benefit for individuals near the end-of-life,[17] CALM is intended to help individuals with cancer live with their disease in the last year or more of life. Large phase 3 trials of CALM are underway in Canada [18] and Europe,[19] but preliminary mixed-methods trials have shown promising improvements in depression, spiritual well-being, and death-related distress in individuals who have participated in CALM.[20,21]

Objective
The overall objective of the present study was to examine death-related distress and its management through conversations with others in patients with advanced cancer who were participating in a phase III randomized control trial (RCT) of the CALM intervention. The primary outcome of the CALM trial is the severity of depressive symptoms.[18] The specific goals of this study were to examine in these patients: 1. the experience of death-related distress; 2. the perceived challenges to communicating distress to family and loved ones; 3. the perceived influence of CALM therapy on communication.

METHODS
Procedure and Sampling
Participants were recruited as part of the CALM RCT at the Princess Margaret Cancer Centre (PM), part of the University Health Network (UHN) in Toronto, Canada. The study received approval from the UHN Research Ethics Board and all participants provided written informed consent.

Eligible participants for the CALM RCT were identified based on screening of their electronic health records. Participants were recruited from outpatient cancer clinics at PM and had a diagnosis of stage IV breast, genitourinary, melanoma, sarcoma, or gynecologic cancers, stage III or IV lung, or ovarian cancer; or pancreatic cancer at any stage. Further eligibility requirements were being 18 years of age or older, a prognosis of 12–18 months, and fluency in English. Exclusion criteria included poor Eastern Cooperative Oncology Group performance status, being actively seen by a psychiatrist or psychologist in the Department of Supportive Care at PM, and cognitive impairment (as indicated in the chart, or through a score of <20 on the Short Orientation-Memory-Concentration test).

A subset (n=17) of those randomized to the intervention arm of the trial were recruited to participate in the present qualitative study. Recruitment was purposeful in order to select individuals with low or elevated levels of distress based on Patient Health Questionnaire-9 [22] or Death and Dying Distress Scale [2] scores. Participants were interviewed by an interviewer who was not a CALM therapist after they had completed at least 3 CALM therapy sessions.

Interviews
A research analyst not involved in the delivery of CALM therapy contacted eligible patients and conducted in-person semi-structured interviews with those who provided informed consent. The interview protocol was designed to capture the cancer experience as well as the experience with CALM therapy. In the hour-long interview, participants were asked “How has your life changed since the cancer diagnosis?”, “What kinds of support do you and/or your family have?” and “Can you tell me about your experience of the CALM therapy?”

Analysis
Interviews were conducted at PM and audio-recorded, then professionally transcribed verbatim. Transcripts were analyzed using thematic analysis,[23] facilitated by the use of NVivo version 10,[24,25] a qualitative analysis software. Thematic analysis is a descriptive method of identifying and reporting patterns in data.[23] A preliminary coding scheme was developed by listing different experiences of participants with their cancer, the support they had, and the CALM therapy. Then, sub-themes were developed by combining and cataloguing related patterns and experiences. Finally, sub-themes were combined under more general themes. In an iterative manner, transcripts were coded into the preliminary coding scheme. This coding scheme, sub-theme, and general themes were applied to all transcripts until no new codes emerged. General themes were then explored for relationships. Coding was carried out by two researchers (EA, EW) and then reviewed by other members of the research team (GR, RN).

RESULTS
Sample
Seventeen patients participated in qualitative interviews. Participants were all Caucasian and 53% were male. The most common cancer types were gastrointestinal (29%), genitourinary (29%), and gynecologic (18%) (Table 1).

<table>
<thead>
<tr>
<th></th>
<th>Percent (n)</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years</td>
<td>58 (7.4)</td>
<td></td>
</tr>
<tr>
<td>Years since cancer diagnosis</td>
<td>3.8 (3.7)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>47 (8)</td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>100 (17)</td>
<td></td>
</tr>
<tr>
<td>Caregiver attended sessions</td>
<td>47 (8)</td>
<td></td>
</tr>
<tr>
<td>Participants with children</td>
<td>76 (13)</td>
<td></td>
</tr>
<tr>
<td>Participants with children under 18</td>
<td>18 (3)</td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
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<tr>
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<td></td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>5 (1)</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>18 (3)</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>12 (2)</td>
<td></td>
</tr>
<tr>
<td>Living arrangements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living alone</td>
<td>18 (3)</td>
<td></td>
</tr>
<tr>
<td>Living with spouse/partner</td>
<td>29 (5)</td>
<td></td>
</tr>
<tr>
<td>Living with spouse/partner and children</td>
<td>41 (7)</td>
<td></td>
</tr>
<tr>
<td>Living with children</td>
<td>12 (2)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
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<td></td>
</tr>
<tr>
<td>High school</td>
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<td></td>
</tr>
<tr>
<td>College/trade</td>
<td>18 (3)</td>
<td></td>
</tr>
<tr>
<td>Undergraduate</td>
<td>35 (6)</td>
<td></td>
</tr>
<tr>
<td>Post-graduate/professional school</td>
<td>35 (6)</td>
<td></td>
</tr>
<tr>
<td>Religion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anglican</td>
<td>12 (2)</td>
<td></td>
</tr>
<tr>
<td>United Church</td>
<td>6 (1)</td>
<td></td>
</tr>
<tr>
<td>Christian</td>
<td>12 (2)</td>
<td></td>
</tr>
<tr>
<td>Christian Orthodox</td>
<td>6 (1)</td>
<td></td>
</tr>
<tr>
<td>Protestant</td>
<td>12 (2)</td>
<td></td>
</tr>
<tr>
<td>Jewish</td>
<td>12 (2)</td>
<td></td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>6 (1)</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>28 (5)</td>
<td></td>
</tr>
<tr>
<td>Do not wish to respond</td>
<td>6 (1)</td>
<td></td>
</tr>
<tr>
<td>Diagnosis Site</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>29 (5)</td>
<td></td>
</tr>
<tr>
<td>Genitourinary</td>
<td>29 (5)</td>
<td></td>
</tr>
<tr>
<td>Gynecological</td>
<td>18 (3)</td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>12 (2)</td>
<td></td>
</tr>
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</table>
Table 1 Sample characteristics (n=17)

<table>
<thead>
<tr>
<th>Lung</th>
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<tbody>
<tr>
<td>PHQ9 score</td>
<td>5.1(4)</td>
</tr>
<tr>
<td>DADD5 score</td>
<td>28(18)</td>
</tr>
</tbody>
</table>

Thematic analysis of the interview transcripts revealed three overarching themes and eight sub-themes. The experience of death-related distress involved: diffuse and overwhelming fear, fear of uncertainty, and fear of suffering. While it was important for participants to discuss these fears, they perceived numerous obstacles to doing so. Participants identified two main roles of the CALM therapist in helping them to address these difficulties: (1) providing a secure base that supported communication and relief of distress, and (2) facilitating communication of death-related distress with others (see Table 2). These findings are elaborated below.

Table 2 Findings and themes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
</tr>
</thead>
<tbody>
<tr>
<td>The experience of death-related distress</td>
<td>Diffuse and overwhelming fear</td>
</tr>
<tr>
<td></td>
<td>Fear of uncertainty</td>
</tr>
<tr>
<td></td>
<td>Fear of suffering</td>
</tr>
<tr>
<td>Perceived communication challenges</td>
<td>Perceived reluctance of others</td>
</tr>
<tr>
<td></td>
<td>Participant reluctance to burden others</td>
</tr>
<tr>
<td></td>
<td>Participants’ own distress</td>
</tr>
<tr>
<td>Perceived influence of CALM on communication</td>
<td>CALM therapist as a secure base</td>
</tr>
<tr>
<td></td>
<td>CALM therapist as facilitator in discussions with others</td>
</tr>
</tbody>
</table>

1. The experience of death-related distress

Although there was some variability, a common perceived trajectory of distress was described by participants. When first diagnosed, participants recalled experiencing an overwhelming and diffuse fear. Over time, this fear was attenuated and replaced by a more low-grade but persistent fear about the uncertain course of their disease and the suffering that might occur. Those with extreme initial distress sought or were referred for professional psychosocial support. As their fear became more manageable over time, participants felt more able to rely on family and friends for relief of their distress.

1.1 Diffuse and overwhelming fear

Participants described their initial fear of death as diffuse, overwhelming and incessant:

“I think it is the worst if someone tells you that you have cancer, the first moment is oh, and I will die. It is so stressful, so terrible that for some nights you are unable to sleep because you are thinking about it. [...]So emotionally it’s very, very difficult.” (female, 64, stage 4 colorectal cancer)
They tended to speak about these feelings retrospectively, acknowledging that they felt the most devastated at the time of initial diagnosis:

“I think that’s what happens when you’re first diagnosed. You’re like, oh my God, I’m dying. This is it. I’m circling the drain” (female, 64, stage 4 ovarian cancer)

The majority of participants felt that they were able to cope with the acute emotional impact of their disease and to manage their diffuse and nonspecific fear over time. With some participants, reduction in this fear over time reflected their perception that their disease had been effectively treated.

“[O]nce I had the operation and I started feeling better, well, then that sort of changed. Because I wasn’t feeling sick. So it was hard to think that I actually had cancer, except that I would go for chemo every two weeks” (female, 64, stage 4 colorectal cancer)

1.2 Fear of uncertainty

Participants linked anxiety about the future to uncertainty regarding the progression of disease:

“I know that if this treatment stops working, the cancer could come back like a freight train. That’s frightening, very frightening” (female, 64, stage 4 ovarian cancer)

“I was] really frustrated and angry and scared, because I didn’t know anything more about my cancer other than, oh we think you have cancer” (female, 53, stage 3 ovarian cancer)

1.3 Fear of suffering

Participants reported a fear of suffering, including worry about a painful death, intolerable symptoms, and loss of independence as their disease progressed.

“I do always have specific fears not to be in much pain [...] I’ll always ask do they give you something, like morphine or something so you can cope?” (female, 56, stage 4 GI cancer)

This fear was usually precipitated by treatment failure or the discovery of new symptoms. However, some participants also reported that their worry about future suffering was based on their belief that cancer and its treatments are painful.

“I fear a lot of pain and discomfort because of the pain. Everyone connected to cancer [has] a lot of pain and suffering and that’s why people are scared of it” (female, 60, stage 3 ovarian cancer)
2. Perceived challenges to communicating distress to family and close ones

The majority of participants stated that they primarily received instrumental support (e.g. help with household chores, daily activities) rather than emotional support from their caregivers and loved ones.

2.1 Reluctance of others to discuss mortality

One of the most common perceived barriers to communication of death-related distress was the reluctance of caregivers and close ones to discuss this topic. Participants spoke of their need to express their fears about the future and mortality, but found that others were not receptive to this:

“[O]ther people tend to want to dismiss it, ’but you’re doing so well, you’re doing so well’. I know that. I get that. There’s a little bit of the ‘what if, what then?’ People don’t want to discuss it” (female, 64, stage 4 ovarian cancer)

Close others often insisted on remaining positive and optimistic, eschewing any mortality-related thoughts. However, participants considered the disease to be so much a part of their felt experience that they felt unable or unwilling to join in this unbalanced positivity. They tended to regard their own view as realistic rather than negative:

“[Friends] want to be positive, which is great. They want things to work out for you. They don’t want to hear... It’s difficult for them to hear, I think, the negative things, or what they might interpret as negative thinking which I think is realistic thinking.” (female, 53, stage 4 breast cancer)

In some cases, the lack of communication about the reality of the situation created a distance in their relationship such that participants were unaware of how their family members were coping:

“I really don’t know where the two boys are at. I try to talk to them but they really don’t want to talk about it” (male, 49, stage 3 lung cancer, referring to his young children).

In addition, participants felt that their loved ones avoided the topic of dying and death to protect the participant from emotional distress.

“But I think it’s emotionally very hard to watch someone go through that and to worry about what’s going to happen to them. You know? [...] [My husband]’s talking to other people and trying not to burden me. I think it’s... it’s definitely been hard for him and, you know, it’s hard to let people know” (female, 53, stage 4 breast cancer)

However, this sometimes frustrated participants as they felt this protectiveness was misplaced. One participant spoke of his adult daughter:
“[My daughter]’s decided that she’s got to take care of me, though I don’t need taking care of, but she doesn’t appreciate that” (male, 58, stage 4 prostate cancer)

2.2 Participant reluctance to burden others
Participants expressed a need to protect their family from the burden of talking about dying and felt that talking about their distress would undermine their own status as caregivers within their family. Particularly, those caring for younger children or elderly parents did not want to disrupt the lives of their families.

“I know my parents and I know that they would just be, they would just start moping and I don’t want that for them. I want them to just have a nice life [...] I don’t want them worrying about me, I want them to worry about themselves” (female, 47, stage 4 sarcoma)

Avoiding disclosure of their fears was a way to maintain their familial role:

“I try to protect my family and don’t talk about it [death] because this is a way for [my children] to believe that that I am a very strong person and I deal with all my issues” (female, 60, stage 3 ovarian cancer)

2.3 Participants’ own reluctance to communicate their distress
Participants also spoke of their own reluctance to discuss dying and death as this topic invoked distress in them:

“I told [my daughter] only that I am afraid of painful dying but we didn’t talk about it a lot. It was too emotional for me” (Female, 60, stage 4 ovarian cancer)

While participants acknowledged that they should discuss the future, they reported that they were not ready to open up to their family.

“Interviewer: Is there a particular reason why you haven’t discussed your fears with your family or has it just not come up in conversation?
Participant: I think it will come in one, two years later. No time for it now” (Female, 60, stage 4 ovarian cancer)

3. Perceived influence of CALM therapy on communication
Participants reported that participation in CALM therapy alleviated their death-related distress in one of two main ways: 1) CALM was experienced as a secure space in which to discuss dying and death; 2) CALM therapists facilitated communication between the participants and their close others about death-related issues. Participants reported that open discussions about end-of-life with either close ones or with the therapist provided emotional relief.
3.1 CALM therapist as a secure base

The CALM therapist was most commonly described as a secure base. Some participants felt that CALM provided a safe environment where they could discuss dying and death. The CALM therapist was regarded as better equipped than family members to navigate an open discussion of dying and death, as they were perceived to be objective and to have professional expertise. This was particularly valuable because loved ones were often perceived as uncomfortable with such discussions.

“[The CALM therapist] has lots of experience with people going through the same thing or related things, so I knew that I could be really honest and straightforward with her” (Participant 1027, 57, female, stage 4 breast cancer)

In this instance, CALM helped individuals manage their terror by providing a secure base and a source of support.

3.2 CALM therapist as a facilitator of communication between participants and others

Participants reported that an important role of the CALM therapist was to facilitate death-related discussions with loved ones. Participants indicated that joint CALM sessions with caregivers and family helped ease them into the conversation about dying and death.

“The boys were more open than they are when they’re just talking to me, and [my CALM therapist] knows the touch points so it gets them talking even more” (Participant 1104, 58, male, stage 4 lung cancer)

The CALM therapist was also perceived to facilitate end-of-life conversations in an indirect manner; by verbalizing their fears about the future, participants felt better equipped to disclose their distress outside of CALM.

“[B]ecause of the sessions I have opened up more with my daughter, as far as being able to talk to her about things. [...] just saying it out loud sometimes makes it easier for you to discuss things or to think about things” (Participant 1020, 64, female, stage 4 colorectal cancer)

**DISCUSSION**

In this qualitative study of patients with advanced cancer participating in a tailored supportive-expressive intervention, we found that CALM therapists were perceived as a secure base, providing relief from distress within the sessions and in other relationships. This sense of safety allowed participants to freely discuss death-related fears. These fears emerged in interviews with most participants, although they were not explicitly asked about them. Such open communication was perceived to be instrumental in helping participants to manage death-related distress.
Participants attributed the relative lack of communication with their close others about dying and death to the perceived reluctance of their loved ones to discuss the end of life, and to their own desire to remain self-reliant. Distress about the potential suffering and death of their loved one may have impaired caregivers’ ability to regulate participant distress. Consistent with previous research, CALM was found to be helpful by providing a safe environment where mortality could be openly discussed.[26] It has been shown that while patients do not necessarily want to discuss their fears with healthcare staff, they do want the option to do so.[27] This desire for the opportunity to discuss death-related issues is supported by the fact that death talk in first CALM therapy sessions was initiated by patients following open-ended questions about their feelings and understanding of their cancer.[28] This experience with the CALM therapist increased participants’ confidence to communicate with their loved ones about dying and death.

The sense of connection with others is an important dimension of psychosocial wellbeing in individuals with advanced cancer.[29] The experience of patients regarding the CALM therapist was characterized by empathy, warmth, openness, and authenticity [30] in allowing participants to express their fears and discuss the future. Phase 2 trials of CALM indicated that individuals receiving CALM therapy were more likely to become more securely attached than usual care participants.[20, 21] Our findings are consistent with this and support the view that attachment security is heightened by the therapeutic relationship that is established in CALM therapy. This function of attachment relationships and attachment security in supporting affect regulation and in modulating distress has been demonstrated experimentally,[31] and following physical trauma [32] and the onset of an acute life-threatening disease (Rodin et al, under review).

The present findings are compatible with TMT in that the relief of death anxiety in patients with advanced cancer was supported by the experience of a secure attachment to the CALM therapist and fulfillment of participants’ attachment needs. This relationship also allowed participants to communicate their fears to their loved ones, enhancing attachment security in a circular fashion.

Limitations of this study include lack of racial and socioeconomic diversity in our sample, and that participants who agreed to participate in the CALM trial may have differed from other individuals with metastatic cancer. Further, the broad nature of the interview questions may have limited the elucidation of the theme of communication in advanced cancer. Nevertheless, the sample studied is uniquely valuable, since much previous research on death anxiety and TMT has been conducted with healthy individuals, whose death anxiety may represent a different phenomenon.

CONCLUSIONS
This qualitative study demonstrates that individuals with advanced cancer are preoccupied with concerns related to dying and death and find relief in the opportunity to communicate this distress. Participants experienced the CALM therapist as a secure base who supported communication of death-related distress both within the therapy and in their close relationships. Open discussion of fears was commonly perceived by participants as therapeutic when it could be accepted by their therapist or family without causing perceived distress or discomfort in them. CALM therapy facilitated
communication of death-related distress within families whether or not caregivers participated in the therapy sessions. Although health professionals and families may be reluctant to discuss such topics, patients facing mortality may find relief from being able to discuss fears that cannot be eliminated from awareness. Support for a wide range of health care providers to engage in more open discussion of mortality-related concerns with patients with advanced disease is needed.

ETHICS
Study approval was obtained from the University Health Network Research Ethics Board.

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COMPETING INTEREST: none declared

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Methods: Semi-structured interviews were conducted with a subset of patients with advanced cancer (n=17) participating in a CALM phase III trial at a large urban regional cancer center. Interviews were transcribed and qualitative data was analyzed using thematic analysis.

Results: Death-related distress was experienced in terms of three key themes: diffuse and overwhelming fear, fear of uncertainty, and fear of suffering. The perceived barriers to communicating such distress were: reluctance of loved ones to discuss mortality-related issues and the participants’ own reluctance to discuss death-related concerns to protect their loved ones or themselves from distress. CALM therapists were perceived to facilitate discussions on dying and death in sessions and to support patients’ communication of death-related distress with health care providers and loved ones.

Conclusions: Advanced cancer patients perceive barriers to effective communication of death distress to be related to their own reluctance, as well as reluctance of their loved ones to address such fears. CALM therapy may help patients with advanced cancer to overcome obstacles to communication and to alleviate death-related distress.

Keywords: advanced cancer; death-related distress; terror management; psychosocial; qualitative research

BACKGROUND

Advanced cancer is associated with fears and challenges related to disease progression and symptom burden, dependency and disability, suffering, and worry about dying and death.[1,2] These undermine self-esteem and sense of meaning,[3,4] may disrupt personal relationships, and generate emotional distress. The psychological consequences of an advanced cancer diagnosis may include elevated suicide rates.[5] There is evidence to suggest that psychological distress may overshadow concerns over physical symptoms in terminally ill patients.[6]

Death-related distress is common in individuals with advanced cancer.[2,7] Terror management theory (TMT) [8] provides a useful framework for understanding how individuals cope with death-related fears. TMT suggests that the fear, or ‘terror’, invoked by heightened mortality salience [9] is modulated by three protective psychological factors: the sense of meaning, self-esteem, and attachment security.[10] Although TMT has primarily been studied in healthy individuals, these factors are relevant for patients...
with advanced cancer who may be preoccupied with existential fears as the threat of mortality becomes highly salient.[11,12]

Attachment security is the least empirically supported pillar of TMT. This construct refers to the internalized expectations of receiving, deserving, and making flexible use of emotional support.[10] An important component of attachment security is that the communication of distress to a supportive figure can help alleviate distress.[13] This suggests that communication of death-related distress in the context of a supportive relationship could help to ameliorate such anxiety.

In the context of advanced disease, heightening of attachment needs due to increased mortality salience may disrupt relationships in which there has been a longstanding equilibrium, causing distress in both patients and their caregivers.[14] In fact, caregivers may report greater distress than cancer patients themselves.[15] Patients with high levels of death anxiety may benefit from support, but the overwhelming nature of their distress may hinder open discussion about the end-of-life and advanced care planning with their loved ones.[16] A therapeutic intervention to relieve distress in one or both partners, and to facilitate emotional communication within this relational system [14] may therefore be valuable.

The CALM Intervention
Managing Cancer and Living Meaningfully (CALM) is a brief semi-structured psychotherapy that is intended to support attachment security and to facilitate communication between patients facing advanced disease and their caregivers. CALM is optimally delivered in 3-6 sessions over a six-month period. Primary caregivers are invited to attend sessions when this is desired by the patient.[4] The individual and couple-based nature of CALM therapy allows for tailoring of the timing and content of the intervention to accommodate the unique needs of those facing metastatic cancer and their caregivers. Unlike Dignity Therapy, which has shown benefit for individuals near the end-of-life,[17] CALM is intended to help individuals with cancer live with their disease in the last year or more of life. Large phase 3 trials of CALM are underway in Canada [18] and Europe,[19] but preliminary mixed-methods trials have shown promising improvements in depression, spiritual well-being, and death-related distress in individuals who have participated in CALM.[20,21]

Objective
The overall objective of the present study was to examine death-related distress and its management through conversations with others in patients with advanced cancer who were participating in a phase III randomized control trial (RCT) of the CALM intervention. The primary outcome of the CALM trial is the severity of depressive symptoms.[18] The specific goals of this study were to examine in these patients: 1. the experience of death-related distress; 2. the perceived challenges to communicating distress to family and loved ones; 3. the perceived influence of CALM therapy on communication.

METHODS
Procedure and Sampling
Participants were recruited as part of the CALM RCT at the Princess Margaret Cancer Centre (PM), part
of the University Health Network (UHN) in Toronto, Canada. The study received approval from the UHN
Research Ethics Board and all participants provided written informed consent.

Eligible participants for the CALM RCT were identified based on screening of their electronic health
records. Participants were recruited from outpatient cancer clinics at PM and had a diagnosis of stage IV
breast, genitourinary, melanoma, sarcoma, or gynecologic cancers, stage III or IV lung, or ovarian cancer;
or pancreatic cancer at any stage. Further eligibility requirements were being 18 years of age or older, a
prognosis of 12-18 months, and fluency in English. Exclusion criteria included poor Eastern Cooperative
Oncology Group performance status, being actively seen by a psychiatrist or psychologist in the
Department of Supportive Care at PM, and cognitive impairment (as indicated in the chart, or through a
score of <20 on the Short Orientation-Memory-Concentration test).

A subset (n=17) of those randomized to the intervention arm of the trial were recruited to participate in
the present qualitative study. Recruitment was purposeful in order to select individuals with low or
elevated levels of distress based on Patient Health Questionnaire-9 [22] or Death and Dying Distress
Scale [2] scores. Participants were interviewed by an interviewer who was not a CALM therapist after
they had completed at least 3 CALM therapy sessions.

Interviews
A research analyst not involved in the delivery of CALM therapy contacted eligible patients and
conducted in-person semi-structured interviews with those who provided informed consent. The
interview protocol was designed to capture the cancer experience as well as the experience with CALM
therapy. In the hour-long interview, participants were asked “How has your life changed since the
cancer diagnosis?”, “What kinds of support do you and/or your family have?” and “Can you tell me
about your experience of the CALM therapy?”

Analysis
Interviews were conducted at PM and audio-recorded, then professionally transcribed verbatim.
Transcripts were analyzed using thematic analysis,[23] facilitated by the use of NVivo version 10,[24,25]
a qualitative analysis software. Thematic analysis is a descriptive method of identifying and reporting
patterns in data.[23] A preliminary coding scheme was developed by listing different experiences of
participants with their cancer, the support they had, and the CALM therapy. Then, sub-themes were
developed by combining and cataloguing related patterns and experiences. Finally, sub-themes were
combined under more general themes. In an iterative manner, transcripts were coded into the
preliminary coding scheme. This coding scheme, sub-theme, and general themes were applied to all
transcripts until no new codes emerged. General themes were then explored for relationships. Coding
was carried out by two researchers (EA, EW) and then reviewed by other members of the research team
(GR, RN).

RESULTS
Sample
Seventeen patients participated in qualitative interviews. Participants were all Caucasian and 53% were male. The most common cancer types were gastrointestinal (29%), genitourinary (29%), and gynecologic (18%) (Table 1).

<table>
<thead>
<tr>
<th></th>
<th>Percent (n)</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years</td>
<td>58 (7.4)</td>
<td></td>
</tr>
<tr>
<td>Years since cancer diagnosis</td>
<td>3.8 (3.7)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>47 (8)</td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>100 (17)</td>
<td></td>
</tr>
<tr>
<td>Caregiver attended sessions</td>
<td>47 (8)</td>
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</tr>
<tr>
<td>Participants with children</td>
<td>76 (13)</td>
<td></td>
</tr>
<tr>
<td>Participants with children under 18</td>
<td>18 (3)</td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
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<td></td>
</tr>
<tr>
<td>Married/common law</td>
<td>65 (11)</td>
<td></td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>5 (1)</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>18 (3)</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>12 (2)</td>
<td></td>
</tr>
<tr>
<td>Living arrangements</td>
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</tr>
<tr>
<td>Living alone</td>
<td>18 (3)</td>
<td></td>
</tr>
<tr>
<td>Living with spouse/partner</td>
<td>29 (5)</td>
<td></td>
</tr>
<tr>
<td>Living with spouse/partner and children</td>
<td>41 (7)</td>
<td></td>
</tr>
<tr>
<td>Living with children</td>
<td>12 (2)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
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<td></td>
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<tr>
<td>High school</td>
<td>12 (2)</td>
<td></td>
</tr>
<tr>
<td>College/trade</td>
<td>18 (3)</td>
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</tr>
<tr>
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<td>35 (6)</td>
<td></td>
</tr>
<tr>
<td>Post-graduate/professional school</td>
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</tr>
<tr>
<td>Religion</td>
<td></td>
<td></td>
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<tr>
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<td>12 (2)</td>
<td></td>
</tr>
<tr>
<td>United Church</td>
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<td></td>
</tr>
<tr>
<td>Christian</td>
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<td></td>
</tr>
<tr>
<td>Christian Orthodox</td>
<td>6 (1)</td>
<td></td>
</tr>
<tr>
<td>Protestant</td>
<td>12 (2)</td>
<td></td>
</tr>
<tr>
<td>Jewish</td>
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<td></td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>6 (1)</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>28 (5)</td>
<td></td>
</tr>
<tr>
<td>Do not wish to respond</td>
<td>6 (1)</td>
<td></td>
</tr>
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<td></td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>29 (5)</td>
<td></td>
</tr>
<tr>
<td>Genitourinary</td>
<td>29 (5)</td>
<td></td>
</tr>
<tr>
<td>Gynecological</td>
<td>18 (3)</td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>12 (2)</td>
<td></td>
</tr>
</tbody>
</table>
Lung 12 (2)
PHQ9 score 5.1(4)
DADDS score 28(18)

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
</tr>
</thead>
<tbody>
<tr>
<td>The experience of death-related distress</td>
<td>Diffuse and overwhelming fear</td>
</tr>
<tr>
<td></td>
<td>Fear of uncertainty</td>
</tr>
<tr>
<td></td>
<td>Fear of suffering</td>
</tr>
<tr>
<td>Perceived communication challenges</td>
<td>Perceived reluctance of others</td>
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<tr>
<td></td>
<td>Participant reluctance to burden others</td>
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<td></td>
<td>Participants’ own distress</td>
</tr>
<tr>
<td>Perceived influence of CALM on communication</td>
<td>CALM therapist as a secure base</td>
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<td>CALM therapist as facilitator in discussions with others</td>
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</table>

Table 1 Sample characteristics (n=17)

Thematic analysis of the interview transcripts revealed three overarching themes and eight sub-themes. The experience of death-related distress involved: diffuse and overwhelming fear, fear of uncertainty, and fear of suffering. While it was important for participants to discuss these fears, they perceived numerous obstacles to doing so. Participants identified two main roles of the CALM therapist in helping them to address these difficulties: (1) providing a secure base that supported communication and relief of distress, and (2) facilitating communication of death-related distress with others (see Table 2). These findings are elaborated below.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
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<tbody>
<tr>
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</tbody>
</table>

Table 2 Findings and themes

1. The experience of death-related distress

Although there was some variability, a common perceived trajectory of distress was described by participants. When first diagnosed, participants recalled experiencing an overwhelming and diffuse fear. Over time, this fear was attenuated and replaced by a more low-grade but persistent fear about the uncertain course of their disease and the suffering that might occur. Those with extreme initial distress sought or were referred for professional psychosocial support. As their fear became more manageable over time, participants felt more able to rely on family and friends for relief of their distress.

1.1 Diffuse and overwhelming fear

Participants described their initial fear of death as diffuse, overwhelming and incessant:

“I think it is the worst if someone tells you that you have cancer, the first moment is oh, and I will die. It is so stressful, so terrible that for some nights you are unable to sleep because you are thinking about it. [...]So emotionally it’s very, very difficult.” (female, 64, stage 4 colorectal cancer)
They tended to speak about these feelings retrospectively, acknowledging that they felt the most devastated at the time of initial diagnosis:

“I think that’s what happens when you’re first diagnosed. You’re like, oh my God, I’m dying. This is it. I’m circling the drain” (female, 64, stage 4 ovarian cancer)

The majority of participants felt that they were able to cope with the acute emotional impact of their disease and to manage their diffuse and nonspecific fear over time. With some participants, reduction in this fear over time reflected their perception that their disease had been effectively treated.

“[O]nce I had the operation and I started feeling better, well, then that sort of changed. Because I wasn’t feeling sick. So it was hard to think that I actually had cancer, except that I would go for chemo every two weeks” (female, 64, stage 4 colorectal cancer)

1.2 Fear of uncertainty

Participants linked anxiety about the future to uncertainty regarding the progression of disease:

“I know that if this treatment stops working, the cancer could come back like a freight train. That’s frightening, very frightening” (female, 64, stage 4 ovarian cancer)

“I was] really frustrated and angry and scared, because I didn’t know anything more about my cancer other than, oh we think you have cancer” (female, 53, stage 3 ovarian cancer)

1.3 Fear of suffering

Participants reported a fear of suffering, including worry about a painful death, intolerable symptoms, and loss of independence as their disease progressed.

“I do always have specific fears not to be in much pain […]I’ll always ask do they give you something, like morphine or something so you can cope?” (female, 56, stage 4 GI cancer)

This fear was usually precipitated by treatment failure or the discovery of new symptoms. However, some participants also reported that their worry about future suffering was based on their belief that cancer and its treatments are painful.

“I fear a lot of pain and discomfort because of the pain. Everyone connected to cancer [has] a lot of pain and suffering and that’s why people are scared of it” (female, 60, stage 3 ovarian cancer)
2. Perceived challenges to communicating distress to family and close ones

The majority of participants stated that they primarily received instrumental support (e.g. help with household chores, daily activities) rather than emotional support from their caregivers and loved ones. One of the most common perceived barriers to communication of death-related distress was the reluctance of caregivers and close ones to discuss this topic. Participants spoke of their need to express their fears about the future and mortality, but found that others were not receptive to this:

“[O]ther people tend to want to dismiss it, 'but you’re doing so well, you’re doing so well'. I know that. I get that. There’s a little bit of the ‘what if, what then?’ People don’t want to discuss it” (female, 64, stage 4 ovarian cancer)

Close others often insisted on remaining positive and optimistic, eschewing any mortality-related thoughts. However, participants considered the disease to be so much a part of their felt experience that they felt unable or unwilling to join in this unbalanced positiveness. They tended to regard their own view as realistic rather than negative:

“[Friends] want to be positive, which is great. They want things to work out for you. They don’t want to hear... It’s difficult for them to hear, I think, the negative things, or what they might interpret as negative thinking which I think is realistic thinking.” (female, 53, stage 4 breast cancer)

In some cases, the lack of communication about the reality of the situation created a distance in their relationship such that participants were unaware of how their family members were coping:

“I really don’t know where the two boys are at. I try to talk to them but they really don’t want to talk about it” (male, 49, stage 3 lung cancer, referring to his young children).

In addition, participants felt that their loved ones avoided the topic of dying and death to protect the participant from emotional distress.

“But I think it’s emotionally very hard to watch someone go through that and to worry about what’s going to happen to them. You know? [...] [My husband]’s talking to other people and trying not to burden me. I think it’s... it’s definitely been hard for him and, you know, it’s hard to let people know” (female, 53, stage 4 breast cancer)

However, this sometimes frustrated participants as they felt this protectiveness was misplaced. One participant spoke of his adult daughter:
“[My daughter]’s decided that she’s got to take care of me, though I don’t need taking care of, but she doesn’t appreciate that” (male, 58, stage 4 prostate cancer)

2.2 Participant reluctance to burden others

Participants expressed a need to protect their family from the burden of talking about dying and felt that talking about their distress would undermine their own status as caregivers within their family. Particularly, those caring for younger children or elderly parents did not want to disrupt the lives of their families.

“I know my parents and I know that they would just be, they would just start moping and I don’t want that for them. I want them to just have a nice life [...] I don’t want them worrying about me, I want them to worry about themselves” (female, 47, stage 4 sarcoma)

Avoiding disclosure of their fears was a way to maintain their familial role:

“I try to protect my family and don’t talk about it [death] because this is a way for [my children] to believe that that I am a very strong person and I deal with all my issues” (female, 60, stage 3 ovarian cancer)

2.3 Participants’ own reluctance to communicate their distress

Participants also spoke of their own reluctance to discuss dying and death as this topic invoked distress in them:

“I told [my daughter] only that I am afraid of painful dying but we didn’t talk about it a lot. It was too emotional for me” (Female, 60, stage 4 ovarian cancer)

While participants acknowledged that they should discuss the future, they reported that they were not ready to open up to their family.

“I interviewer: Is there a particular reason why you haven’t discussed your fears with your family or has it just not come up in conversation?
Participant: I think it will come in one, two years later. No time for it now” (Female, 60, stage 4 ovarian cancer)

3. Perceived influence of CALM therapy on communication

Participants reported that participation in CALM therapy alleviated their death-related distress in one of two main ways: 1) CALM was experienced as a secure space in which to discuss dying and death; 2) CALM therapists facilitated communication between the participants and their close others about death-related issues. Participants reported that open discussions about end-of-life with either close ones or with the therapist provided emotional relief.
3.1 CALM therapist as a secure base

The CALM therapist was most commonly described as a secure base. Some participants felt that CALM provided a safe environment where they could discuss dying and death. The CALM therapist was regarded as better equipped than family members to navigate an open discussion of dying and death, as they were perceived to be objective and to have professional expertise. This was particularly valuable because loved ones were often perceived as uncomfortable with such discussions.

“[The CALM therapist] has lots of experience with people going through the same thing or related things, so I knew that I could be really honest and straightforward with her” (Participant 1027, 57, female, stage 4 breast cancer)

In this instance, CALM helped individuals manage their terror by providing a secure base and a source of support.

3.2 CALM therapist as a facilitator of communication between participants and others

Participants reported that an important role of the CALM therapist was to facilitate death-related discussions with loved ones. Participants indicated that joint CALM sessions with caregivers and family helped ease them into the conversation about dying and death.

“The boys were more open than they are when they’re just talking to me, and [my CALM therapist] knows the touch points so it gets them talking even more” (Participant 1104, 58, male, stage 4 lung cancer)

The CALM therapist was also perceived to facilitate end-of-life conversations in an indirect manner; by verbalizing their fears about the future, participants felt better equipped to disclose their distress outside of CALM.

“[B]ecause of the sessions I have opened up more with my daughter, as far as being able to talk to her about things. [...] just saying it out loud sometimes makes it easier for you to discuss things or to think about things” (Participant 1020, 64, female, stage 4 colorectal cancer)

DISCUSSION

In this qualitative study of patients with advanced cancer participating in a tailored supportive-expressive intervention, we found that CALM therapists were perceived as a secure base, providing relief from distress within the sessions and in other relationships. This sense of safety allowed participants to freely discuss death-related fears. These fears emerged in interviews with most participants, although they were not explicitly asked about them. Such open communication was perceived to be instrumental in helping participants to manage death-related distress.
Participants attributed the relative lack of communication with their close others about dying and death to the perceived reluctance of their loved ones to discuss the end of life, and to their own desire to remain self-reliant. Distress about the potential suffering and death of their loved one may have impaired caregivers’ ability to regulate participant distress. Consistent with previous research, CALM was found to be helpful by providing a safe environment where mortality could be openly discussed.[26] It has been shown that while patients do not necessarily want to discuss their fears with healthcare staff, they do want the option to do so.[27] This desire for the opportunity to discuss death-related issues is supported by the fact that death talk in first CALM therapy sessions was initiated by patients following open-ended questions about their feelings and understanding of their cancer.[28] This experience with the CALM therapist increased participants’ confidence to communicate with their loved ones about dying and death.

The sense of connection with others is an important dimension of psychosocial wellbeing in individuals with advanced cancer.[29] The experience of patients regarding the CALM therapist was characterized by empathy, warmth, openness, and authenticity [30] in allowing participants to express their fears and discuss the future. Phase 2 trials of CALM indicated that individuals receiving CALM therapy were more likely to become more securely attached than usual care participants.[20, 21] Our findings are consistent with this and support the view that attachment security is heightened by the therapeutic relationship that is established in CALM therapy. This function of attachment relationships and attachment security in supporting affect regulation and in modulating distress has been demonstrated experimentally,[31] and following physical trauma [32] and the onset of an acute life-threatening disease (Rodin et al, under review).

The present findings are compatible with TMT in that the relief of death anxiety in patients with advanced cancer was supported by the experience of a secure attachment to the CALM therapist and fulfillment of participants’ attachment needs. This relationship also allowed participants to communicate their fears to their loved ones, enhancing attachment security in a circular fashion.

Limitations of this study include lack of racial and socioeconomic diversity in our sample, and that participants who agreed to participate in the CALM trial may have differed from other individuals with metastatic cancer. Further, the broad nature of the interview questions may have limited the elucidation of the theme of communication in advanced cancer. Nevertheless, the sample studied is uniquely valuable, since much previous research on death anxiety and TMT has been conducted with healthy individuals, whose death anxiety may represent a different phenomenon.

CONCLUSIONS
This qualitative study demonstrates that individuals with advanced cancer are preoccupied with concerns related to dying and death and find relief in the opportunity to communicate this distress. Participants experienced the CALM therapist as a secure base who supported communication of death-related distress both within the therapy and in their close relationships. Open discussion of fears was commonly perceived by participants as therapeutic when it could be accepted by their therapist or family without causing perceived distress or discomfort in them. CALM therapy facilitated
communication of death-related distress within families whether or not caregivers participated in the therapy sessions. Although health professionals and families may be reluctant to discuss such topics, patients facing mortality may find relief from being able to discuss fears that cannot be eliminated from awareness. Support for a wide range of health care providers to engage in more open discussion of mortality-related concerns with patients with advanced disease is needed.

ETHICS
Study approval was obtained from the University Health Network Research Ethics Board.

ACKNOWLEDGEMENTS
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COMPETING INTEREST: none declared

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