

“We Cannot Have any Negativity”: A secondary analysis of expectancies for the experience of emotion among women with gynecologic cancer

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Abstract

This study aimed to elucidate whether gynecologic cancer patients and their support persons have certain expectancies for emotion and whether these expectancies, if they exist, affect cancer-related communication. Semi-structured interviews ($N=34$) were conducted separately with 18 patients and one of their support persons ($n=16$). Thematic analysis revealed a subset of patients and support persons expected patients to not have any negative emotions, which patients also reported they perceived from support persons, and that these expectancies could affect cancer-related communication. These results have implications and can facilitate appropriate recommendations for how cancer patients and support persons co-manage patients' emotions.

Keywords

cancer, communication, emotions, qualitative methods, social support

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Introduction

Gynecologic cancer affects females' reproductive organs, although symptoms typically vary by cancer type (Centers for Disease Control and Prevention [CDC], 2017). Each year, roughly 89,000 US females are diagnosed with gynecologic cancer, while more than 29,000 die from it (CDC, 2017). It was estimated that there will be 109,000 new diagnoses and 33,100 deaths by the end of 2019 alone (American Cancer Society [ACS], 2019). The 5-year survival rate for metastatic uterine and ovarian cancer is 6% and 29%, respectively (ACS, 2019). The physical morbidity of gynecologic cancer is therefore considerable.

Cancer also commonly affects psychological health. Patients can experience a broad range of emotions that may be "negative" (e.g. sadness) and/or "positive" (e.g. gratitude), the presence of which are understandable and "normal" (Brennan, 2004; Holland and Alici, 2010; National Cancer Institute, 2017). However, when the frequency and/or intensity of these emotions, especially of those that are negative, become too great, they may become distressing and/or interfere with daily functioning. Indeed, patients with uterine and/or ovarian cancer are at an increased risk for psychological distress or morbidity (Manne et al., 2014). Furthermore, patients with gynecologic cancer report increased depression scores at the time of diagnosis compared to patients with other cancers (Linden et al., 2012) and among the top 10 reported stressors faced by gynecologic cancer patients, eight were of the non-physical nature such as cancer-related psychological distress (Steele and Fitch, 2008). Thus, management of the emotional health of patients with gynecologic cancer is critical.

The way patients appraise the very presence of their emotions—"good" or "bad", "positive" or "negative"—in and of itself has implications for their psychological functioning. Although the presence of "negative" emotions is "normal" within the cancer experience and even among all physically healthy individuals and can indeed be adaptive for everyday functioning in many ways

(see Lazarus, 1991; Smith and Lazarus, 1993), emotions are often labeled as "positive" or "negative"—or "good" or "bad"—with a social preference often given to the former (Bastian et al., 2012). Reflective of this preference, cultural norms send messages to society to not feel sad and to strictly aspire for happiness (Bastian et al., 2012). Happiness is often believed by most, especially in Western society, as critical for individual well-being and to achieving a meaningful life and negative emotion as a hindrance to achieving such outcomes (White, 2007). Hence, what individuals believe others hold as expectations for emotions serve to establish "reference values" for their own emotional experiences (Carver and Scheier, 1982, 1990). Bastian et al. (2012) developed the term *expectancies* for the experience of negative emotion, with *personal expectancies* referring to how an individual thinks they should feel in a given situation (e.g. "I shouldn't be sad about my cancer") and *social expectancies* referring to how *others* think an individual should feel (e.g. "My partner thinks I shouldn't be sad about my cancer"). The perceived failure to meet these expectancies has further negative implications for individuals' well-being.

Equally important for how patients appraise their negative emotions is how important others appraise patients' negative emotions, such as their support persons (e.g. their partner, children, friends). Support persons can be crucial in co-managing patients' emotions, especially those who are more involved and accompany patients to appointments. However, in support persons trying to help patients co-manage their emotions, it is important to understand not only how support persons appraise negative emotions but the verbal and nonverbal messages they send to patients regarding patients' negative emotions, in line with social expectancies (Bastian et al., 2012). Support persons who send messages to patients that it is unacceptable for them to experience negative emotions are not only missing out on opportunities for providing emotional support for patients (e.g. Lillie et al., 2018) but may also counterintuitively place greater social pressure on them. Indeed,

such well-intended support given by support persons is not always perceived as supportive by patients (Barbee et al., 1998).

Balancing these communication acts can thus be an art and, when patients perceive that this balance is executed unsuccessfully, these acts can influence topic avoidance. Topic avoidance is purposefully avoiding the discussion of particular topic with another individual (Afifi and Guerrero, 2000; Dailey and Palomares, 2004), and one motivation for topic avoidance is an individual perceiving the person with whom they are considering communicating as unhelpful and/or unresponsive (Afifi and Guerrero, 2000; Barbee et al., 1998). Indeed, topic avoidance occurs in the context of multiple types of cancer (e.g. Donovan-Kicken and Caughlin, 2010; Goldsmith and Miller, 2014; Manne et al., 2014, 2015; Venetis et al., 2014, 2015). For example, it has been demonstrated that the more patients perceive their partner will be unresponsive, the less likely patients are to initiate cancer discussions (Venetis et al., 2014, 2015). Thus, if patients have negative emotions they wish to discuss but perceive an inability to do so with a support person because that person does not think the patient should have negative emotions, topic avoidance can occur.

Accordingly, the purpose of this manuscript was, through secondary analysis of data from a larger research project, to examine whether gynecologic cancer patients and support persons have certain expectancies for patients' emotion and, if these expectancies exist, identify whether patients and/or support persons report these expectancies affect cancer-related communication.

Methods

Participants and procedure

Participants were female patients with gynecologic cancer and affiliated support persons. Patient eligibility included: currently receiving chemotherapy for their first diagnosis of gynecologic cancer (i.e. ovarian, uterine,

endometrial), being between chemotherapy cycles two and five (i.e. having experienced initial treatment and met the oncology team previously), and reporting a support person who regularly attends appointments. Support persons were recruited by patient nomination from these target patients. All participants were at least 18-years-old, speak English, verbally consented to participate, and additionally verbally consented to be audio-recorded. Sample size was determined based on when saturation was met for the larger study, that is, when no new or relevant data emerge in the interviews (Francis et al., 2010). This resulted in a sample of 34 participants (89% dyads), of whom 18 were patients with gynecologic cancer and 16 were affiliated support persons. Full demographics for patients and support persons are presented in Table 1.

Participants were recruited from a National Cancer Institute comprehensive cancer center in the northeastern US. Potential patient participants were identified by chart review, and research staff provided information about the study during a routine outpatient oncology visit. A phone interview was scheduled with eligible patients who expressed interest and who reported having a support person attending appointments. Support persons were approached in the clinic if they were with the patient or via phone.

Patients and support persons were mailed their respective copy of the consent form to review prior to the interview. Verbal consent was obtained just prior to their separate interviews, after interviewers confirmed with participants their understanding of their participation. After providing verbal consent, none of the participants expressed discomfort with or asked to stop the interview and none withdrew from the study. All study procedures were approved by the Rutgers University Institutional Review Board and the cancer center's Scientific Review Board.

Three trained interviewers (MKV, DC, and MC) conducted semi-structured recorded phone interviews as part of the larger study. These interviewers have experience in interpersonal

Table 1. Patient and support person characteristics (N = 34).

Characteristic	Patient (n = 18) n (%)	Support person (n = 16) n (%)
Demographic information		
Gender		
Female	18 (100%)	7 (44%)
Male	-	9 (56%)
Race/Ethnicity		
Non-Hispanic white	10 (56%)	11 (69%)
Hispanic white	4 (22%)	2 (13%)
Black or African American	3 (17%)	2 (13%)
Non-Hispanic mixed race	1 (6%)	1 (6%)
Educational background		
High school	6 (34%)	3 (19%)
Some college/Trade school	7 (39%)	4 (25%)
College degree	3 (17%)	6 (38%)
Postgraduate/Professional	2 (11%)	3 (19%)
Support person type		
Partner	-	7 (44%)
Adult child	-	4 (25%)
Sister	-	2 (13%)
Parent	-	1 (6%)
Other (nephew/friend)	-	2 (12%)
Cancer-related information		
Cancer type		
Ovarian	9 (50%)	-
Uterine	2 (11%)	-
Endometrial	9 (50%)	-
Time since diagnosis		
≤ 1 month	1 (6%)	-
2–3 months	8 (44%)	-
4–5 months	5 (28%)	-
6 ≥ months	4 (23%)	-

health communication and are well-established scholars in disclosure and topic avoidance in health contexts, including oncology. They also have considerable interviewing experience. Thus, they were considered best suited to conduct the interviews. Phone interviews, specifically, were conducted to ensure maximum flexibility and privacy for participants.

Interview questions of the larger study asked patients to focus on one support person who regularly accompanies them to appointments and asked support persons to focus on the patient. Participants were asked about the nature

of their relationship with the other and what kinds of support (and how helpful and unhelpful the support is perceived) that patients receive from support persons. Interview questions also asked participants what kinds of information is easy and difficult to share with each other, both alone and in the presence of a healthcare professional. After the interview, each participant was mailed a \$50 gift card. Interviews were transcribed verbatim, deidentified, and verified by three authors (AB, KG, MC). Average interview length for patients was 40 minutes and for support persons was 42 minutes.

Secondary data analysis

Transcripts were coded using thematic analysis to investigate emergent themes relating to patients' and support persons' expectancies for emotion (Braun and Clark, 2006). Two of the authors were responsible for the data analysis (AB, KD), who both have background in the clinical health psychology discipline and have previous research experience in the oncology setting. They independently read the transcripts, selected excerpts illustrating emergent themes relating to the literature on expectancies for emotion, and kept memos of content reflecting identified themes. These authors then compared themes and excerpts to discuss and resolve any differences in interpretation. To begin, the literature on expectancies for emotion guided the analysis initially, but then we also looked for emerging additions, contradictions, and/or clarifications to the data.

Because we conducted a secondary analysis of data from interviews that did not specifically ask about expectancies for emotion, we recognized that there would be difficulty in determining what constituted "expectancies for emotion." To try to reconcile this difficulty, we coded only for statements in which it was expressed that no negativity—or only positivity—was expected or acceptable. While this is likely a stringent criterion in coding the data, it was the only criterion that we deemed would ensure such expectancies were truly present in the data. Contrast this with statements, for example, in which it was expressed that patients were encouraged to remain positive—without this black and white lens. Statements such as this are vaguer in that it is possible that such expectancies exist, but that it is also possible that patients were encouraged to remain positive but that negativity (e.g. sadness, anxiety) was also acceptable. In other words, these vaguer statements in which emotional coping strategies were not presented in black and white terms—"no negativity" or "only positivity"—does not rule out the possibility that both positive and negative emotions were considered acceptable, in which case expectancies to not

experience negative emotion would not be present and would be incorrectly coded.

Results

Four themes emerged from the secondary analyses. All themes are discussed below, with representative participant quotes. Italics within quotes were added for emphasis. A subset of participants—approximately one half—expressed at least one of the following themes.

Patients' expectancies for their own emotion

Patients reported beliefs that they should always experience positive emotions and/or they should never experience negative emotions. These patients also described that no negative emotions were acceptable, regardless of, for example, how frequently or infrequently they were experienced. These patients also made statements that implied positive and negative emotions could not co-occur. This was demonstrated with the use of language reflecting absolutes, such as "*any* negativity," "*anything* negative," or "*nothing* negative." One patient said, "I don't even look at *any* negativity side of anything" [P 1]. The patient's use of "any" demonstrates her belief that she should not experience even a small amount of negativity. Another patient reported:

When I was first diagnosed . . . [my husband] came in a little later and he showed me this weepy, weepy sad country video and I said, "I don't want to hear about that. I don't want *anything* negative, *nothing* negative anymore." . . . so we stopped our crying and that was it. Done, over with. [P 15]

This patient not only demonstrates her belief that she should not experience any negative emotions, but also goes as far as not allowing herself to cry.

Patients' reports were also reflective of implicit or explicit rules about their emotions. These beliefs were manifest in language

reflecting self-imposed rules, such as repeated use of imperatives including “I *can't*,” “I *shouldn't*,” or “I *should*.” One patient reported:

I *can't* complain. I *can't* complain. And that's probably why, you know, I'm able to get. . . to get better and to move forward and, you know, not to look at the kind of negative stuff [crying]. . . . I *shouldn't* complain. I *shouldn't* complain. [P 11]

These implicit or explicit rules were also demonstrated in an interview with one patient who described a reason behind these rules. She reported:

I have a wonderful sister in [southern state] who, every day, I talk to. So, I have great family. I have great family. I have to thank God every day. It. . . *it could've been worse*. . . . I shouldn't complain. I shouldn't complain. I should be thankful, it could have been worse. [P 11]

Here, because her situation could have been worse and is not the worst situation possible, she should not “complain” about having cancer and—to even more of an extreme—should be thankful. This quote thus also demonstrates a rationalization for not allowing herself to be upset.

Patients' perceptions of support persons' expectancies for patients' emotion

Patients reported that support persons specifically told them to always be positive and/or to never be negative. This was demonstrated with language reflecting absolutes regarding patients' emotional experiences, such as “*no negativity*.” One patient reported, regarding her husband:

Every now and then it hits me and I would start crying and I'm like, “Oh my God, will I be here next year?” . . . And I tell him and then I get a speech. . . . basically, he says, “Listen, negative. . .”, that there's *no negativity* in our life. [P 9]

Here, the patient acknowledges that she does experience negative emotions but also reports

that her communication of these negative emotions is met with resistance by her husband giving a “speech.” She summarizes by reporting that there is “no negativity” in their life, which leaves no room for negative emotions, no matter how minute or transitory.

Patients' reports were also reflective of implicit or explicit rules support persons have regarding patients' emotions. This was demonstrated with language reflecting perceived support person-imposed rules, such as repetitive use of terms including “I'm *not allowed*,” “I *can't*,” or, “We *can't*.” One patient stated regarding her husband's communication and beliefs:

We cannot have any negativity. We do not. *I'm not allowed*. He doesn't do it either. We do not watch the news and all the craziness that happens in this country. I can't watch any detective shows which I used to like. I can only watch—this is his rule by the way—comedy, anything like cooking shows. [P 9]

An explicit statement is made that she is “not allowed” to think or feel negatively and acknowledges one of her husband's “rules.” Another patient reported:

My mom, sometimes if I get upset, she'll say, ‘Oh, take something,’ . . . They gave me to take, sedatives if I'm feeling anxious or whatever, but I only take that when I need it . . . I don't want to sit taking extra medicine you know because I'm on enough medicine. [P 16]

This patient reported that when she does get upset, her mother will instruct her to take a sedative to block her negative emotions. This example is more extreme in that not only are expectancies for not having negative emotions perceived reported, but the patient's mother even recommends that the patient actively blunts these emotions.

Support persons' expectancies for patients' emotion

Support persons' reports were consistent with the belief that patients should always experience positive emotions and/or that they should never

experience negative emotions, paralleling not only patients' reports of their own expectancies but also patients' perceptions of support persons' expectancies. Support persons described how no negative emotions were acceptable and that positive and negative emotions could not co-occur. These beliefs manifested in language reflecting absolutes, such as "100% positive." One support person said regarding her daughter, "100% positive. I don't want to hear negativity. I want to hear positivity" [SP 16]. This remark demonstrates that this support person believes her daughter is not allowed to experience any negative thoughts or emotions about her cancer. "100% positive" leaves 0% room for the experience of negativity.

Support persons' reports were also reflective of implicit or explicit rules regarding patients' emotions. These beliefs were demonstrated with language reflecting rules imposed on patients, such as "got to," "should," or "shouldn't." One support person expressed:

And when she gets down I just try to encourage her to, you know, look more towards the positive side of it. And there's a lot of things, even when you're going through, there's a lot of things. . . *you got to* look at on the positive end [SP 3]

This support person, through her detailing what the patient should or should not do, describes expectations for what the patient is expected to think and feel, as well as for herself. Similarly, a support person reported regarding his wife:

And she gets down in the dumps, especially the week before, when she *should* be her strongest, when she is her strongest, a week before chemo, she's looking ahead to the chemo and getting herself really down in the dumps when she *shouldn't* be. [SP 9]

This support person used the prescriptive words "should" and "shouldn't," which concretely reflect a set of beliefs about which emotions should be experienced and how. Additionally, a support person remarked regarding her daughter:

She *can't* sit in the house and feel sorry for herself. . . she *has to* get herself out. But sitting in the house and 'woe is me-ing' is not going to help you. You *gotta* stay positive. . . I tell her, "You *gotta* do this and you *gotta* just know that you're going to beat it in the end. And, it's not gonna beat you and you *gotta* just believe that. You *gotta* believe positive." [SP 16]

These prescriptive beliefs also manifested with language reflecting downward comparisons (see Taylor and Lobel, 1989), such as, "it could be worse." One support person discussed a friend's daughter, another cancer patient:

You got to look at on the positive end. . . because *it could be worse*. And it don't matter if it don't feel like it's worse, but *somebody else is having, you know, having it worse than you*. [SP 3]

Demonstrated here is the implicit belief that because the patient's situation could be worse and/or another patient's situation perhaps is worse, the patient should not have negative emotions.

Effect of expectancies on cancer-related communication

In addition to patients and support persons discussing their expectancies for patients' emotions, the effect of expectancies on patient-support person cancer communication was also raised. There is considerable overlap of this theme with the other themes; however, the emphasis of this theme is not merely on the experience of *emotion* and related *expectancies*, but specifically on the *communication* of these expectancies. This includes what patients believe they can and cannot discuss with support persons. One patient reported on interactions with her aunt, with whom she does not believe open communication can occur for negative topics. She said, "When I call [location] and speak with my aunt, I might say something and she'll say, 'Oh, don't say that. I don't want to hear that, let's not talk about that'" [P 10]. Similarly, a husband support person reported,

“We’re talking about the positives. You know, *nobody ever* talks about the negatives” [SP 7]. “Nobody” reveals a belief that it is not acceptable to discuss negative topics, including negative emotions. He also uses the absolute “ever,” portraying a polarized belief about communication of negative topics.

Discussion

The results of this secondary analysis revealed that a subset of patients and support persons—approximately half—reported beliefs that patients should not experience negative emotions, and that patients perceive these expectancies from their support persons, as well. These patients and support persons expressed polarized thinking regarding the experience of negative emotion in that no negative emotions were acceptable. The use of language such as “can’t,” “should,” and “shouldn’t” governing patients’ emotions further demonstrates prescriptive beliefs patients and support persons hold regarding patients’ emotions, but the prescriptions also seem to be enforced for support persons’ emotions. Additionally, these expectancies interfered with patients’ cancer-related communication with their support person.

Patient-perceived personal and/or social expectancies to not experience any negative emotions has implications for patients’ psychological health, especially since patients with gynecologic cancer are already at an increased risk for psychological distress and morbidity (Manne et al., 2014). Greater perceived expectancies for not experiencing negative emotions is associated with greater negative evaluation of oneself which, in turn, is associated with greater frequency and severity of those same negative emotions and with a greater level of depression symptoms (Bastian et al., 2012). When individuals fail to meet perceived emotional expectancies, this perceived shortcoming can lead to feelings of failure and increased negative rumination (Bastian et al., 2012). Negative rumination can exacerbate those same negative emotions (Moberly and Watkins, 2008; Nolen-Hoeksema, 2000), contributing to rather than

ameliorating these negative emotions. Furthermore, perceived expectancies for negative emotion is indeed positively correlated with feelings of loneliness (Bastian et al., 2015).

Patients with gynecologic cancer have reported needing assistance in managing their emotional health (Miller et al., 2003). Furthermore, patients with cancer have acknowledged the need for emotional support (Baker et al., 2013), especially when they are currently or have recently received cancer treatment, reflecting where our participants were in the cancer trajectory. Thus, the opportunity for support persons to provide appropriate and patient-perceived emotional support is great. Previous work has demonstrated that during the course of emotional support provision, support persons of breast cancer patients were faced with managing open communication channels while also maintaining positivity for the patient (Lillie et al., 2018). This work also revealed that support persons were also faced with validating patients’ negative emotions while simultaneously promoting productive action for the patient. Thus, one recommendation for support persons is creating an atmosphere in which patients perceive they can openly talk about and have their negative emotions validated, but not so much so that patients get “stuck” in their negative emotions and productive action is thus sacrificed. Indeed, acceptance of negative emotions is associated with less negative emotions and depressive symptoms (Shallcross et al., 2010). Thus, support persons working with patients to accept these negative emotions is another effective way they can help provide emotional support.

Creating such an atmosphere can not only deter the negative psychological effects but can also perhaps provide opportunities for benefits, in addition to the already well-demonstrated positive effects of positive emotions. Negative emotions can be beneficial in many, more concrete ways, such as in relation to attaining a meaningful life and improving one’s well-being (Hayes et al., 1999), enhancing interpersonal relationships (Fischer and Manstead, 2008; McNulty, 2010), and heightening creativity

(Wilson, 2008). With regard to the cancer context, one study demonstrated that negative affect (e.g. fear, anxiety, sadness, guilt) predicted adaptive health behaviors in a breast cancer sample, such as goal adjustment capacity (Castonguay et al., 2017), demonstrating the capacity for positive effects of negative emotions for cancer patients.

Furthermore, if patients avoid discussing their emotional experiences with their support person because of perceived expectancies, they are not only isolating themselves but are possibly missing opportunities for emotional and other types of support. Patients may then be left with fewer sources of and therefore opportunities for support, which has implications for their mental and physical health. For example, in Siwik et al. (2017), gynecologic cancer patients' emotion-focused coping strategy of emotional expression—the inverse of topic avoidance—was negatively associated with depressive symptoms. Additionally, patients may miss out on opportunities for more informational or tangible support, such as learning about or obtaining palliative care, especially for patients with gynecologic cancers in which such care may be more relevant and appropriate due to these cancers' low survival rates. Topic avoidance in this respect can also have relational implications. Patients may choose to withhold discussing cancer with support persons if they believe they cannot openly discuss their negative emotions, such as in Lillie et al. (2018) which demonstrated that when patients felt they could not discuss negative emotions with their partner, they turned to friends for support, instead. Indeed, extant research has demonstrated that topic avoidance is negatively correlated with relationship satisfaction (Caughlin and Affif, 2004; Donovan-Kicken and Caughlin, 2010), which can place even greater stress on patients and support persons.

This research is not without limitations. First, and perhaps most importantly, these data were part of a larger study and thus this manuscript presents data as part of secondary analysis. As such, emotional expectancies were not specifically probed for in our questions and, relatedly,

we are unable to ascertain whether saturation was met. While our results suggest patients and support persons do hold expectancies for patients to not experience negative emotions, we do not believe these results would be substantially different had saturation (or the certainty of such) been ensured. Future research should include primary and follow up questions pertaining to expectancies for emotion, which would allow for less stringent coding criteria than what was undertaken in this analysis, potentially revealing more patients and/or support persons endorsing these expectancies but for whom they may be less extreme. Additionally, such research would allow for a better understanding of motivations for these expectancies and of how expectancies affect communication and, ultimately, the relationship between patient and support person. Such research could also include questions to gauge counter examples—situations in which negativity was expected and acceptable—to more comprehensively understand this phenomenon.

Second, the sample size was small and predominantly non-Hispanic white, limiting our understanding of the extent to which our findings may reflect the lived experiences of other races/ethnicities. Third, there was variation in support person type, so it is unclear whether support person type is reflective of a different relational dynamic or support role. Last, the specific nature of a gynecologic cancer diagnosis may not provide insight into other types or stages of cancer diagnoses. For instance, as stated earlier, gynecologic cancer is one of the most serious types of cancer—especially ovarian cancer—evidenced by its 5-year survival rate. As such, this may prompt negative emotions more frequently and severely than for other cancers, which could have a different or perhaps more profound effect on expectancies and the communication of such. However, focusing on gynecologic cancer facilitates greater assurance that experiences represent this specific group.

For many, cancer is not experienced in isolation, making it important to understand the role support persons have in helping (or hindering)

patients with managing their emotions for overall emotional and physical well-being. Accordingly, these results have implications for how patients and support persons co-manage patients' emotional health both inside and outside of healthcare organization settings. A comprehensive understanding of the experience of emotion and the role of support persons will enable identification of appropriate recommendations for support persons regarding the co-management of patients' emotional health.

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