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Dilemmas and Strategy When Companion Participation During Appointments Differs from Patient and Companion Expectations

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ABSTRACT

Cancer patients often attend medical interactions with at least one companion. The degree to which companions participate varies, ranging from passive observer to active advocate. However, the structure of the medical interaction often promotes dyadic rather than triadic communication, creating ambiguity about the degree to which companions can and should participate. Participants ($N = 34$, 16 dyads) included gynecologic cancer patients who were undergoing chemotherapy treatment ($n = 18$) and their companions ($n = 16$); all participants were separately interviewed. Interviews included discussion of dyadic communication patterns within medical interactions. The normative rhetorical theory (Goldsmith, 2019) was applied as a guiding framework. Patients discussed the dilemma they experience when companions are expected but absent. Patients and companions provided positive reports of companion communication when behavior aligned with expectations. Alternatively, patients and companions experience dilemmas when companions participate more than or differently from how patients and/or companions had expected. Companions provided one strategy for managing the dilemma of how to participate in medical interactions. Implications and limitations are discussed.

Cancer diagnoses serve as significant stressors that impact patients and close others, such as family and friends (Weber & Solomon, 2008). Patients and their support providers struggle with understanding the diagnosis, treatment options and protocols, and adapting to life managing cancer (Venetis et al., 2020). Treatment for gynecologic cancer is often complex and can include surgery, chemotherapy, radiation, and/or hormone therapy (Centers for Disease Control and Prevention, 2019). Further, medical visits with clinicians often include a great deal of information that can be overwhelming. Thus, due to the taxing physical and psychological toll of cancer treatment, cancer patients often attend medical visits with a supportive other, henceforth referred to as companion, such as a spouse or partner, adult child, or friend (Eggle et al., 2006; Laidsaar-Powell et al., 2013).

Companions vary in the degree of participation during medical visits from passive observer to active advocate (Street & Gordon, 2008) and perform a range of behaviors such as providing informational assistance and emotional support (Laidsaar-Powell et al., 2013; Wolff & Roter, 2011). Although patients often evaluate these behaviors as beneficial, some companion participation behaviors, such as criticizing or controlling patients or dialogue, are evaluated as interfering (Mazer et al., 2014). Social support scholarship recognizes the potential face-threatening acts that occur when requesting or providing social support (Goldsmith, 2019). The normative rhetorical theory (NRT, Goldsmith, 2019) describes communicative dilemmas that occur when communicative tasks, such as being supportive, challenge interactants' identity, such as unintentionally suggesting someone

cannot care for themselves (Goldsmith et al., 2006). Framed in NRT, this manuscript investigates patient and companion tensions that emerge as companions participate during gynecologic cancer-care interactions.

Companion participation in the medical interaction

The onset of severe illness, such as cancer, can influence individuals' identity, emotions, and functional capabilities. For many, such diagnoses dampen independence and autonomy and make relevant the need for aid and assistance such as transportation, help with mobility, care provision and coordination, and emotional and/or informational support (Laidsaar-Powell et al., 2013; Miller & Zook, 1997). Severe illness can modify sociocultural expectations for behavior such that individuals are expected to embody "the sick role" (Parsons, 1975) and reduce daily labor and routine activities while close others assume care for the sick individual and for their responsibilities. Thus, for many individuals, a diagnosis of cancer triggers both patient expectations of care assistance and companion assumptions of providing care.

Patients' ability and/or motivation to participate in their own interactions with healthcare providers can be influenced by various factors. Biopsychosocial features contribute to patient participation such that patients who are older, less educated, and/or those who are experiencing increased impairment are more often accompanied to medical interactions (Laidsaar-Powell et al., 2013; Wolff & Roter, 2011). In such cases, their companions are more participative than patients

who are younger and/or experiencing better health (Clayman et al., 2005). Further, individuals experiencing cancer vary in their emotional response to diagnoses and treatment. Some patients may adopt an assertive coping style, such as a fighting spirit, that is characterized by a determination to overcome the cancer and assertive behavior (Watson et al., 1988). Such patients are often self-advocates (Brashers et al., 1999) and are proactive, involved in their treatment, and communicatively engaged in medical interactions (Ong et al., 1999). Alternatively, other cancer coping styles include being anxious, hopeless, avoidant, and/or fatalistic (Watson et al., 1988). Individuals engaging in these coping styles are typically less participative (Ong et al., 1999).

Patient degree of participation in medical interactions influences companion engagement. Patients and companions often align participation such that if one is the dominant participant, the other is more passive (Street & Gordon, 2008; Wolff & Roter, 2011)¹. Patient-companion participation typologies highlight the variation in the level and/or directness of companion participation (Mazer et al., 2014; Street & Gordon, 2008). Companions are often described as generally passive, and their participation serves to support patients who are actively participating. In the passive role, companions may offer indirect supportive behaviors such as being present, helping patients to recall information, repeating or clarifying clinician communication to patients, and helping patients communicate with clinicians (Ishikawa et al., 2006). A second category of patient and companion participation includes active patients and active companions such that patients and companions sharing approximately equal participation (Street & Gordon, 2008). Finally, the third category reflects active companions and passive patients with companions asking questions, providing information, and at times, speaking for patients, excluding patients from participation (Ishikawa et al., 2006; Mazer et al., 2014).

Patients generally evaluate companion participation and presence as helpful (Ishikawa et al., 2006; Rosland et al., 2011). For example, patients report that with the presence of a companion, they have increased comfort in communicating with the clinician and can better offer details and explanations of symptoms and experiences, can better understand clinician instructions, and have increased motivation to adhere to clinician advice (Ishikawa et al., 2006; Rosland et al., 2011). Patients also note that the presence of companions motivates clinicians to provide greater detail and increased attention to patients (Ishikawa et al., 2006). Although much less frequent, patients also report negative companion supportive behaviors (Clayman et al., 2005; Laidsaar-Powell et al., 2013). Companions may share information with clinicians that patients did not want revealed or be dominant or demanding, and patients can be hesitant to share some information in the presence of companions (Ishikawa et al., 2006; Laidsaar-Powell et al., 2013; Rosland et al., 2011). Patients report that companion participation is less helpful when companion behavior does not align with patient expectations (Ishikawa et al., 2006; Lee et al., 2022). Specifically, patients evaluated companion participation as less helpful when they had anticipated limited companion activity, yet companions were actively participative (Ishikawa et al., 2006). Alternatively, patient evaluations of companion helpfulness are highest when patients

anticipated active companion participation and companions were highly participative. Patients prefer companion involvement, but they also strive to retain priority in determining who participates in interactions about their care (Laidsaar-Powell et al., 2013). Scholars recommend that patients and companions should have explicit conversations about the companions' roles and participation expectations (Laidsaar-Powell et al., 2016; Miller & Zook, 1997; Speice et al., 2000).

Normative rhetorical theory

The normative rhetorical theory (NRT, Goldsmith, 2019) is a heuristic framework that describes how enacting communicative behaviors, or tasks, can trigger identity or relationship issues. NRT is described as a rational model (Goldsmith, 2019). This implies that although there are several ways in which one can choose to engage in a task, some approaches, or strategies, are interpreted more favorably than others. For instance, companions' task of communicatively helping patients in the medical interaction by offering, clarifying, or supplementing information could threaten patients' identity as autonomous and independent. Further, companion information provision could conflict with relational expectations that companions do not provide information that contradicts patients' accounts. Such moments of tension can introduce both dilemmas of how to effectively communicate as well as unintended, negative effects of communicative efforts. For example, in the context of transitioning to life after a cardiac event, partners' attempts and providing support may be perceived as unwanted control and as "parental behavior" (Goldsmith et al., 2006, p. 2085). Similarly, young adult cancer survivors report interpreting others' support as unhelpful when it was perceived as exaggerated sympathy, "over-helping," or overbearing (Iannarino et al., 2017).

Some strategies to enacting a task may be evaluated as more competent and appropriate than others within a given social group or speech community. These evaluations arise from meanings situated both within speech communities and socio-cultural context. Members of speech communities often share norms and expectations of appropriate types of and interpretations of speech (Goldsmith, 2019). For example, although discussing a partner's mental health is likely challenging for many families, this may be particularly true among military families. Wilson et al. (2015) position the unique challenges presented when talking about mental health in the community of military families particularly when the task of seeking help for mental health concerns conflicts with military values which emphasize strength and self-reliance. To minimize identity threats to service members, military spouses report that when talking about seeking mental health care, they use strategies such as framing help seeking messages positively and cooperatively, acting polite and respectful, and listening nonjudgmentally (Wilson et al., 2019). In a study of how internal medicine residents communicate with patients, residents describe how they reframe messages that could be interpreted by patients as controlling to instead stress collaboration (Liao et al., 2022). They also shared that a strategy to promote patient acceptance of clinician recommendation is to frame it as clinician inquiry and discussion rather rigid treatment demands. Use of such

strategies support patient autonomy and promote patient motivation while also reducing patient psychological reactance. Thus, meaning-making is contingent on the experiences and expectations of members of that particular community. As noted above, patient and companion evaluations of support efforts are variable, ranging from helpful to interfering (Mazer et al., 2014). NRT offers a framework to evaluate how potential dilemmas arise when and how companions enact support.

Finally, NRT explains that timing and positioning of communicative acts matter. An utterance or sentence may be interpreted differently dependent on its place within the larger interaction or series of ongoing conversations. For example, inquiries about having children have the potential for multiple interpretations such as being caring or insensitive. Participants' evaluations of such questions depend on the progression of the conversation (Bute, 2009).

Thus, NRT provides a framework to uncover moments of communication challenges as well as to identify strategies that patients and companions adopt to communicatively manage potential dilemmas in ways that respect identities and relationships. This current research applies NRT as an organizing framework to investigate emergent dilemmas of support attempts during medical interactions attended by patients and their companions as well as strategies participants' report that aid in appropriately addressing these dilemmas. We ask the following:

RQ1: Which dilemmas do patients and companions experience from companion participation during the gynecologic cancer interaction?

RQ2: Which strategies do participants describe to manage dilemmas that emerge during the gynecologic cancer interaction?

Method

Participants

Thirty-four participants, including 18 gynecologic cancer patients and 16 companions (89% dyads), provided in-depth interviews. All patients were women currently receiving chemotherapy treatment for their first diagnosis of gynecologic cancer (i.e., ovarian, uterine, endometrial) and were between chemotherapy cycles two and five (i.e., having experienced initial treatment and met the oncology team previously). All companions were recruited by patients. All participants were at least 18 years old, spoke English, and consented to participate and be audio recorded.

Patients were approximately 61 years old ($M = 61.33$, $SD = 10.75$, range 45 to 88). They were diagnosed with endometrial ($n = 4$, 22%), ovarian ($n = 10$, 56%), and uterine ($n = 4$, 22%) cancers and may be diagnosed with more than one cancer. Companions were approximately 58 years old ($M = 57.50$, $SD = 12.76$, range 30 to 72), and included seven women (43.75%) and nine men (56.25%). Additional patient and companion demographics are provided in Tables 1 and 2.

Procedure

Patients were recruited from a National Cancer Institute comprehensive cancer center in the northeastern US. All study procedures were approved by both the university Institutional Review Board and the cancer center's Scientific Review Board. Potential patient participants were identified by chart review, and research staff provided information about the study during a routine chemotherapy visit. A phone interview was scheduled with eligible patients who expressed interest and who reported having a companion who regularly attended appointments with

Table 1. Patient and companion characteristics ($N = 34$).

Characteristic	Patient ($n = 18$) n (%)	Companion ($n = 16$) n (%)
Sex		
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%)
Partner	-	7 (44%)
Adult child	-	4 (25%)
Sister	-	2 (13%)
Parent	-	1 (6%)
Other (nephew/friend)	-	2 (12%)
Cancer-Related Information		
Cancer type*		
Ovarian	10 (56%)	-
Uterine	5 (28%)	-
Endometrial	4 (22%)	-
Time since diagnosis (in months)	$M = 4.22$, $SD = 3.37$	
Age (years)	$M = 61.33$, $SD = 10.75$	$M = 57.50$, $SD = 12.76$

*1 patient reported two forms of cancer; figures do not equal 100%.

Table 2. Patient and companion demographics.

ID #	Patient Age	Diagnosis	Companion Age	Companion Gender	Companion Relationship
Patient 1	63	Uterine	72	Male	Spouse
Patient 2	47	Ovarian & endometrial	48	Male	Long-term boyfriend
Patient 3	45	Ovarian	66	Female	Friend
Patient 4	61	Uterine	64	Female	Sister
Patient 5	65	Ovarian	36	Female	Daughter
Patient 6	49	Uterine	47	Male	Spouse
Patient 7	60	Endometrial	63	Male	Spouse
Patient 8	58	Ovarian	57	Female	Sister
Patient 9	69	Ovarian	72	Male	Spouse
Patient 10*	57	Endometrial	n/a	Female	Friend
Patient 11	55	Endometrial	30	Female	Daughter
Patient 12	89	Ovarian	64	Male	Son
Patient 13*	70	Uterine	n/a	Female	Daughters
Patient 14	69	Uterine	69	Male	Spouse
Patient 15	60	Ovarian	63	Male	Spouse
Patient 16	48	Ovarian	69	Female	Mother
Patient 17	67	Ovarian	48	Male	Nephew
Patient 18	73	Ovarian	52	Female	Daughter

*Patients 10 and 13 reflected on companions, but their companions were not study participants.

them. Companions were approached in the clinic if they were with the patient. When companions were not present at time of recruitment, patients provided their telephone numbers, and members of the research team contacted them to assess interest and availability. After interviews were scheduled, patients and companions were mailed their respective copy of the consent form to review prior to interviews. Patients and companions were interviewed separately. Before interviews commenced, verbal consent was obtained. Interviews lasted approximately 40 minutes; patient interviews ranged from 22:57 to 67:59 minutes ($M = 40.0$, $SD = 13.17$), and companion interviews ranged from 21:14 to 71:02 minutes ($M = 41.61$, $SD = 14.59$). After the interview, each participant was mailed a \$50 gift card. Interview audio files were transcribed, de-identified, and verified by two authors. Transcriptions produced approximately 14 pages of single-spaced text per participant. Patient transcripts ranged from 9 to 26 pages ($M = 14.38$, $SD = 4.53$), and companion transcripts ranged from 10 to 21 pages ($M = 14.50$, $SD = 3.41$).

Three trained Caucasian, non-Hispanic, female interviewers conducted semi-structured recorded phone interviews. Interview questions asked patients to focus on communication with one companion who regularly accompanies them to appointments and asked companions to focus on communication with the patient during medical visits. Participants were asked about the nature of their relationship, ways in which the companion offers support within and beyond medical interactions, and communication with clinicians. Specific questions that informed results of this investigation included asking patients in what ways their companion was both helpful and unhelpful during the medical interaction and asking partners in what ways they are helpful and unhelpful in the medical interactions. Companions' response to a question about how they participate in the medical interaction also informed study results.

Qualitative analyses

Prior to data analysis, authors did not anticipate application of NRT, and the theory did not initially guide these analyses. Rather, interview data were coded independently using

thematic analysis to generate themes (Braun & Clark, 2006). Following thematic analysis protocol, two authors read the transcripts, generating initial codes by identifying interesting and repetitive concepts across the patient and companion transcripts. We then identified how normative rhetorical theory (Goldsmith, 2019) serves a guiding framework for organizing the emergent results. Specifically, we identified tensions that both patients and companions – separately and complementary – identified during companion participation in the medical interaction. We then selected excerpts illustrating moments of internal conflict during behavior intended to be supportive; we met to further define, refine, and categorize these tensions. We then re-analyzed data focusing on tensions between task, identity, and relational purposes.

Results

Results outline communicative dilemmas that patients and companions experience during these medical interactions (see Table 3). First, absent yet expected companions signal relational difficulties. Next, examination of communication patterns highlights that patients and companions report positive interactions when they are coordinated in how they will both communicate during the visit. At times, when companion participation exceeds patient and/or companion expectations, participants reported tension. Finally, companions offer a strategy of how to manage companion participation in the medical interaction. Participant quotes are identified by their role as patient or companion and assigned dyad number (i.e., Patient 1 and Companion 1 are one dyad; see Table 2).

Patient dilemma when expected companions are absent

Patients and companions alike discussed the inherent value of the supportive task of companions driving patients to medical visits. Companion 3 (age 66) described how she drives her friend (ovarian cancer, age 45) to her appointments “so that she doesn't have to worry about how she's going to get there and get back.” However, patients often anticipated more than transportation alone and appreciate companions' presence

Table 3. Patient and companion dilemmas and strategy in the gynecologic interaction.

Emergent Themes	Examples
Patient dilemma when expected companions are absent	"He just comes to take me for my chemo and that's it. I mean, I'm lucky I get that out of him." (Patient 1)
Patient and companion shared expectations of communication during appointments	"We were there to support each other, make sure everything gets discussed that was on our- we try to make up a little question list . . . So we're there as backup for each other." (Companion 14)
Patient dilemma of companion participation exceeding patient preferences	"They . . . think that they can speak on your behalf, like you have lost your voice." (Patient 13)
Companion dilemma of communicating because of reduced patient cognition	"[S]ometimes she doesn't remember those things. So she kind of defers- that I know them. And I- I feel that it would be better if she did remember them. But. being that what's going through her . . . she can't." (Companion 5)
Companion dilemma when patients minimize their symptoms	"Sometimes, the doctor will say to her . . . 'How's it been since we last talked?' 'Oh, fine, everything's fine.' And I'll go . . . in front of him, 'Mom, . . . we've got to talk about the fact that you were nauseous two days ago.'" (Companion 12)
Companion discomfort from dilemma of participation	I don't know if I'm taking control away from her, but I'm concerned because she has, I think she's got a little bit of that chemo brain, at times, where she forgets stuff. So that's where I worry if I'm being unhelpful, if I'm taking control away from her, when control, any source of control, is so important right now. But, I'm really just doing it for her best interest. (Companion 8)
Companion strategy for providing information without overstepping boundaries	"It's her time and she wants to get her stuff answered first . . . I might chime in with something . . . as a . . . reminder . . . but usually I'll wait until . . . the main topics . . . that she needed discussed are . . . handled first. Yeah, I mean, it's her show." (Companion 14)

during appointments. Patients were vocal in their gratitude about regular and constant companionship during medical visits. Patient 7 (endometrial cancer, age 60) shared about her husband, "He comes with me for everything, and he listens to everything I hear and doesn't hesitate. And that's, that's made me so much more secure, that that that fact has made me, made this whole situation better." Companion 6 (age 47) noted the importance of his presence at his wife's medical appointments. He said, "Driving her, being there, showing her that I'm with her and no matter what situation and what difficult time." In these instances, there is harmony between relational expectations and companion behaviors.

Companion absence in medical visits, however, signals a lack of support and reflects relational tension and contradiction of relational role. Patient 1 (uterine cancer, age 63) described her husband as her "Uber driver." She said, "He just comes to take me for my chemo and that's it. I mean, I'm lucky I get that out of him." She continued, "And this last appointment, [the nurse] even asked me, and I'll be honest, she said to me, 'Is your husband here?' And I said 'no,' and she goes, 'OK, but make sure, when you have your chemo, somebody drives you.'" When a researcher asked if her husband would accompany her if she requested it, she said, "It depends upon his moods. Let me put it that way, I'm not going to go any further than that." The nurse's question makes relevant the expectation that cancer patients are normatively accompanied by companions to treatment visits, and the patient's response that the companion was absent triggered the nurse's advice to make sure the patient has transportation. Patient 5 (ovarian cancer, age 65) also shared a story about her brother and that she no longer speaks to him because of his decision not to accompany her to her appointments. Her account reinforces the expectation that close others attend medical visits with cancer patients. She described,

My brother was supposed to come with me to my first treatment. I was petrified . . . And, uh, he made a big stink, he's going to be there, he's going to support me and, uh, unfortunately, he had

a painter that was coming to give him an estimate on his house. So, he couldn't come. And I cried for 3 hours that night. And when I spoke to him again, I just yelled and screamed and hollered and [told him to] just forget that I'm even alive.

These instances demonstrate how tasks of attending medical visits with patients are meaningful to patients and often represent more than logistics. Being present can signal relational value while absence reflects a tension, friction, and relational deficit, particularly from someone who was expected to provide support such as a spouse or sibling. The patient diagnosis and treatment exist within the context of ongoing relationship dynamics with the companion. As patient 1 elaborated, she does not "live in a fantasy world where I have my knight in shining armor."

Patient and companion shared expectations of communication during appointments

Many patients and companions reported that they approached medical visits together, and that this joint activity was positive. Patients reported companion behaviors of being in attendance, being a "second set of ears," preparing notes or questions before medical interactions, taking notes during appointments, and asking questions as particularly helpful. Participants also described how their conversations outside of medical interactions prepared them for visits as well as a shared expectation of joint activity. Companion 4 (age 64) shared that just before her sister (uterine cancer, age 61) was diagnosed with cancer that she said, "I reassured her that if it was cancer, there would be a plan and I'd stick with her. I just kept always saying to her, 'we're gonna follow the plan.' Just trying to reassure her that we were gonna figure it out." This quote highlights the strong use of the collective noun "we" and camaraderie in managing cancer. Like many companions, Companion 4 stated that she accompanies her sister to all visits, "I got to everything with her" that they are "proactive

before we even go in.” She said that they anticipate what questions to ask and what information the providers will share. A benefit of this task-focused dialogue is the implicit stressing of the relationship. Similarly, Companion 14 (age 69) described how he and the patient prepare before appointments and said, “We were there to support each other, make sure everything gets discussed that was on our- we try to make up a little question list, so we’re there as backup for each other.” His wife (endometrial cancer, age 69) commented that, “It’s good to have him ... because sometimes ... you’ll have a question that you forgot to ask. And he’ll remember ... , ‘Oh, we have to ask this,’ or ... you might not understand exactly what the doctors say.” This exemplar reflects a positive tone that represents how many patients and companions described their joint communication in the medical interaction. The synchrony of expectations and behavior reflects coordination of task, a history of relational interdependence, and a current commitment and identity as a dyad that supports each other.

Patient dilemma of companion participation exceeding patient preferences

Although patients described companions as supportive, the degree to which and how companions participated in the visit could create tension. Companion 1 (age 72) reported that his spouse, the patient (uterine cancer, age 63), expressed that he should talk less in the medical interactions. He reported that she said in one medical visit, “Well, you’re not bashful, are ya?” I said “No, I’m not bashful.” You know, I don’t mind talking.” He interpreted her comment to mean, “Well I think she feels when I talk I shouldn’t be talking. I should more or less be listening because this is pertaining to her and not pertaining to me.” Some patients described how companion communication limited their ability to participate. Patient 9 (ovarian cancer, age 69) shared that her spouse, “just jumps to do everything, and he’ll even talk for me. And I’m like, ‘OK, we’re getting a little over the edge here.’” Patient 6 (uterine cancer, age 49) complained that she finds it unhelpful when her spouse reports information to the clinician that she would not have shared. She stated, “He’ll tell the doctor, ‘She’s not doing, you know ...’ He’ll make me look bad in front of the doctor. Like, my appetite isn’t great and, you know, he’ll harp on me with the doctor about me not eating.”

Some patients credited companions’ speaking for them due to their impaired health. Patient 9 justified her companion’s behavior of taking for her saying, “But he remembers more than I do. I was half drugged half the time.” Similarly, Patient 13 (uterine cancer, age 70) described, “This has to be an automatic reaction on people ... because I am the one who is ill. They ... think that they can speak on your behalf, like you have lost your voice.” This patient, like other patients, described several instances in which her two daughters attempted to talk on her behalf, including describing her symptoms, eating patterns, and feelings to her clinician. She reported that she told her daughters, “I don’t want to feel that because I am sick now I cannot talk. I haven’t lost the ability to think, yet [laughing]” and “listen, I can speak on my own and please let- allow me to do that and if I need your help, I’ll

include you in the conversation.” These exemplars demonstrate how companions’ participation, although intended as support, can serve to undermine patient participation and suggest that patients are physically and/or mentally unable to represent their own experiences. Patients struggle when companions’ provided support undermines their identities as autonomous individuals who can speak for themselves and share relevant information with providers.

Companion dilemma when perceiving the need to participate

Some companions described that they often felt like they needed to be highly participative in the medical interaction to clarify, supplement, or correct patient accounts. Companions identified two instances when they experienced conflict about their need to communicate: when patients were unable to provide accurate and complete information and when patients minimized what they perceived as relevant information.

Companion dilemma of communicating because of reduced patient cognition

Following chemotherapy treatment, patients may experience cognitive variations ranging from high to low lucidity (Mayo Clinic, 2021). This temporary cognitive impairment is referred to as “chemo brain.” Companion 9 (age 72) described his spouse’s (ovarian cancer, age 69) cognitive impairment in this way, “For the first week after chemo ... they call it chemo fog. Her brain really goes out to lunch. I mean, she-sometimes she can’t remember from, you know, the morning to the afternoon what we’re doing or something like this.” Companions described that chemo brain influenced communication during the medical interaction because patients can be disoriented and confused. Companions recognize that chemo brain can interfere with patients’ ability to retain and/or recall information, thus necessitating companions’ need to supplement or clarify information. Companion 18 (age 52) talked about how during the medical interaction her mother, the patient (ovarian cancer, age 73), received instructions for taking medications. She said that even when “she [the patient] repeats it [the information] back to them,” the patient is a “little bit disoriented when we get home ... the information that she received was very confused.” The companion shared how her attempts to clarify the information at home created conflict. She summarized, “[The patient] will refute a lot of the information that I’m telling her. And I’ll ... I’ll just say, ‘Mom, ... you’re a little confused right now because of the medicine.’” Companions described how patients’ inability to recall information creates a dependence on companions that often exceeds companions’ comfort level. Companion 5 (age 36) commented that she would like for her mother (ovarian cancer, age 65) to be able to have a more active role in managing her own care, but that her mother cannot recall specific treatment information. She said, “[S]ometimes she doesn’t remember those things. So, she kind of defers- that I know them. And I- I feel that it would be better if she did remember them. But. being that what’s going through her ... she can’t.” Thus, companions recognize that, independent of patient

preference, patients may be unable to independently manage their care, requiring more active companion involvement that does not match usual relationship patterns.

Companion dilemma of communicating to correct patient minimization

Companions also described the need to complement or correct patient accounts when patients minimized symptoms while interacting with the healthcare team. In response to clinician inquiry about patient health status, some patients would minimize symptoms and report that they are doing “fine.” Companions found patient responses of “fine” to be problematic, as that descriptor was not representative of current patients’ health and wellbeing. Companion 12 (age 64) described a time when he was motivated to correct information his mother (ovarian cancer, age 89) had reported. He shared, “Sometimes, the doctor will say to her . . . ‘How’s it been since we last talked?’ ‘Oh, fine, everything’s fine.’ And I’ll go, in front of him, ‘Mom, we’ve got to talk about the fact that you were nauseous two days ago.’” The companion further described that he feels “a bit pushy” and he is concerned that the act of explicitly contradicting the description may bother his mother, but that he feels responsible to make sure she is accurately depicting her health status. He shared how he combats her minimizing behaviors by responding to her reports of being “fine,” with, “You’re not,” you know, “Mom, you’re not gonna get a trophy for . . . for saying, ‘I’m fine. I’m fine. I’m fine.’ . . . We’re here to try to help you, not, uh, give you a gold star on your forehead.” Similarly, Companion 9 (age 72) recounted how his spouse (ovarian cancer, age 69) resisted telling the clinician that she was suffering from seasonal allergies that were inhibiting her ability to sleep. He explained that in the past the patient generally “just pops a couple Benadryl,” but that the couple was hesitant about the patient taking allergy medication without first consulting the clinician. He shared,

So, we were in the doctor, [oncologist] came in and after she says ‘do you have any questions,’ I say, “Well, [patient]’s been having an allergy issue. What can she take?” And [patient] says, “Well, I don’t have any problems. It’s all good. Don’t bother the doctor with that.”

This theme demonstrates patients’ minimization of their symptoms in service of being a “good patient,” worthy of the “gold star” and who does not “bother the doctor.” This theme also shows how despite preferences to avoid being “a bit pushy” companions can experience relational or identity challenges when engaging in the task of being a supportive companion.

Companion discomfort when participating

Many companions expressed a priority for patients to communicate on their own behalf and be the primary information provider. Companion 9 (age 72) shared his surprise at his spouse’s (ovarian cancer, age 69) initial lack of communication with clinicians at the onset of her treatment. He said, “One thing that surprises me is that she’s . . . really not a good advocate for herself.” He described how she relied on him to share information with clinicians, and this was problematic

because, “The doctor needs to hear *her*.” This exemplar represents several companions’ accounts of discomfort at patients’ reticence to speak for themselves. Companion 5 (age 36) discussed her views on speaking for her mother (ovarian cancer, age 65). She said, “I view as being a little bit more detrimental ‘cause I feel, you know, you have to be your own advocate a lot of times as a patientYou have to know what’s going on with yourself.”

Companions’ perceptions about the necessity of participation does not necessarily remedy the discomfort created by this form of their participation. Companions stated that patients should speak on their own behalf and acknowledged that companion interference could undermine patients’ information sharing. Companion 8 (age 57) discussed how she worries that when she asks questions, clarifies what her sister (ovarian cancer, age 58) tells clinicians, or reminds the patient of what else to tell clinicians, that she is controlling the patient. She said,

I don’t know if I’m taking . . . control away from her, but I’m concerned because she has . . . a little bit of that chemo brain . . . where she forgets stuff. So that’s where I worry if I’m being unhelpful, if I’m taking control away from her, when control, any source of control, is so important right now. But, I’m really just doing it for her best interest.

In this instance, it appears the companion’s need to help and provide accurate information to clinicians supersedes the companion’s need to avoid controlling the patient. Companion 6 (age 47) also discussed the challenge of providing help and support without communicating that the patient (uterine cancer, age 49) is incapable and without control. He said, “I try to do everything possible to make her, and everything easy without make her feel that she can’t do it.” Here again the companion recognizes the importance of providing support while also avoiding the perception of reduced patient agency in these medical interactions.

Companion strategy of providing information without overstepping boundaries

Many companions discussed the communicative practices they developed that allow them to participate in medical interactions while also being mindful of respecting the patient’s agency to speak for themselves. These strategies center on the timing and framing of companion participation that serve to reduce threats to patient autonomy. Companions described the communicative practice of waiting until after the clinician and patient conclude talking dyadically before engaging the clinician. Companion 14 (age 69), a self-described “talker,” explained that he and his spouse (uterine cancer, 69) developed a pattern of when it is acceptable his participation. He said, “It’s her time, and she wants to get her stuff answered first . . . I might chime in with something . . . as a . . . reminder . . . but usually I’ll wait until . . . the main topics . . . that she needed discussed are . . . handled first. Yeah, I mean, it’s her show.” Companion 12 (age 64) echoed a similar sentiment, that he waits until the clinician and his mother (uterine cancer, age 89) complete “their” portion medical interaction before he asks questions or talks with the clinician. However, he also described how

the clinician aided in establishing that interaction structure and order. He said, “He talks to my mom . . . I mean, he’s angled toward her . . . I’m sure it’s by design – his body language is toward her almost to- the . . . the side of his back is toward my wife and I.” The companion continued, “He wants to be one-on-one with her. It’s not a group thing. He’s not going around the room. You know, it’s him and her.” Other companions shared how clinicians help to facilitate when companions are invited to participate by asking companions at the end of the visit if they have additional information or questions.

Companions are also cognizant of not only the timing but also the framing of their participation. Companion 18 (age 52) said that she waits for the clinician to solicit additional information, and then she takes the opportunity to clarify instances that her mother (ovarian cancer, age 73) has described. Like other companions, she attempts to share information while maintaining the patient’s autonomy. Her communicative practice includes acknowledging the patient’s account and offering an alternative, supplemental, or reinforcing perspective. She said, “I’ll say something, like, ‘You don’t have to agree with me, but this is how I see it.’ So, I let her know that, in a way, I’m still respecting and giving validity to what she has just said.” She also described her strategy as a way to participate “without disrespecting my mother or disrespecting the fact that she is the patient.” These exemplars demonstrate how companions actively perform communication work to support and assist patients while recognizing the competing need for patient autonomy and validation.

Discussion

Although research has examined and quantified how companions participate in medical interactions (see Laidsaar-Powell et al., 2013), less research has investigated how patients and companions interpret and make meaning from companion participation. Research urges clinicians and researchers to conceptualize the medical interaction as minimally triadic rather than dyadic given that companion participation is normative (Albrecht et al., 2010). Despite the normative nature companion participation, participant accounts accent a lack of certainty and ambiguity in how to manage tasks while being sensitive to identity and relational needs during medical appointments. We discuss empirical and practical implications.

Absent but anticipated companions

Patients’ increased physical infirmity and potential reduced treatment-related cognitive clarity coupled with the complex, uncertain, and ambiguous nature of information exchange during treatment appointments highlights potential multiple benefits of companion presence (Speice et al., 2000). Socio-cultural norms indicate that, when possible, families and close others serve as companions and participate in the care of loved ones who are ill (Parsons, 1975; Wolff & Roter, 2011). Such participation supports not only instrumental and task needs, but also provides relational support. Study results identify one patient dilemma that occurs when relevant close others fail to perform role-relevant behaviors and violate expectations. Although the supportive task of being present signals a form of relational

maintenance, companion absence particularly when expected can create uncertainty and relational de-escalation (Afifi & Metts, 1998). Because the widespread nature of the cultural norm that those in the sick role need companion presence, the lack of companion presence may serve as a relational and/or identity threat from the absent yet expected other.

(Mis)alignment of communication expectations

Dilemmas emerged when patient and companion expectations of companion participation differed from actual behavior. Aligned with prior research, patients who expected less companion participation than what occurred viewed companion behavior as less helpful (Ishikawa et al., 2006). Patients described that companions speaking for them when they were able to communicate themselves and companions sharing information with clinicians that they did not intend to share as particularly unhelpful, supporting prior research (Ishikawa et al., 2006). The current study helps to contextualize these inherent challenges. Patients used terms like “over the edge” to demonstrate that such behaviors exceed desire. As noted in the results, one patient discussed that when companions speak for her, it suggests that she cannot speak and that she has diminished physical and mental capabilities. Thus, companion support can serve to undermine patient identity as capable and autonomous and fundamentally be unsupportive to the relationship. Similarly, companion support efforts may inadvertently serve to portray patients negatively. Patients and companions described instances in which companion information sharing, particularly about patients’ reduced appetites and eating, could make patients “look bad,” damaging patient face and negatively reflecting their identity.

Despite companion concerns that supplementing or contradicting patient accounts is awkward and minimizes patient agency, companions reported engaging in these behaviors. Interestingly, patients frequently commented that they appreciate companion presence and participation because companions may remember information or questions that they forgot. Thus, companion information sharing is not universally problematic. The challenge exists when companion communication exceeds patient preference or offers specific information purposely excluded by the patient. This tension reflects what Goldsmith et al. (2006), in a study of how partners talk about lifestyle changes following a cardiac event, refer to the effect of “partner behavior” being perceived as “parental behavior” (p. 2085, emphasis in original). The challenges of informal caregiving are also described as the “I don’t want to be a nag but . . .” dilemma (Goldsmith et al., 2006). This dilemma described partners’ attempts to nudge or remind patients of needed healthy behaviors, but these reminders could be negatively evaluated as controlling and may suggest patients’ lack of knowledge or behavioral control. The current study’s results echo this dilemma within the healthcare context. As the “I don’t want to be a nag but” dilemma suggests, companions decide to “be a nag” in efforts to support patients. These tensions outline how participation, even when doing “what is best for the patient,” can conflict with companions’ potential identity goals of being a person who respects

another's autonomy and as someone who provides comfort while also providing support (rather than upsetting someone while providing support). Similarly, companions likely strive to protect patients' identity goals of being viewed as autonomous, competent individuals. These competing demands make this a challenging communicative task within what is at minimum a complex triadic interaction.

Companions recalled that patients minimized their symptoms or avoided sharing information with clinicians, positioning companions in the potentially precarious position of disagreeing with patients, challenging patients' face, or offering agreement and thus limiting the information clinicians received. In a study of family and friends providing informal caregiving, Petronio et al. (2004) described this dilemma as the "privacy versus medical well-being dilemma" (p. 42). Similar to current study results, participants reported a tension between ensuring the clinician's access to clear and accurate information and respecting patient privacy. Petronio et al. explained companion perspectives of how at times their need to help and protect the patient's health is prioritized above expectations of patient privacy.

When facing the sick role (Parsons, 1975) and managing a serious illness, individuals often rely on informal caregivers for daily and medical assistance. The inclusion of another in care management may make that individual privy to private information, or a *co-owner* of that information (Petronio, 2010). Although the patient is the information *owner* because the information is about their care, experiences, and treatment, a companion may assume expectations of information co-ownership and the rights and privileges about regulating that information, such as deciding with whom to share the information. Although patients "own" their health information, companions, and particularly interdependent companions, may intuit information co-ownership privileges if they help the patient manage the illness. A co-ownership expectation, coupled with the cultural norm of telling truthful information (Grice, 1975) may also urge companions to alert providers when a patient's illness account contradicts a companion's evidence and experiences (Thompson et al., 2021).

Companions should also be alerted to the multiple reasons that patients may indicate that they are "fine" or may minimize symptoms. Individuals' self-accounts as "fine" may emerge from the clinician's problem presentation style. Heritage and Robinson (2006) examine how clinicians elicited patients' reasons for their acute medical visits, and one approach was asking "How are you?" This question style is problematic because it conflates medical wellbeing with a normative greeting. Future research should examine if cancer patients' accounts as "fine," occur as a response to the style of clinician greeting. Further, individuals, particularly older adults, are concerned with "bothering" their clinician, as noted by Companion 12, and may limit their accounts due to their concerns of clinicians' schedules (DiMatteo, 1998). Individuals often constrain their information sharing to that information which they deem relevant to the other participant (Grice, 1975). Patients may report to clinicians that they are "fine" and may be hesitant to address their medical concerns because they are uncertain of what health information is salient to their medical interaction

(Robinson & Heritage, 2005). For example, Companion 9 shared that his spouse (endometrial cancer, age 69) did not want to talk to the clinician about her inability to sleep due to congestion from allergies. Finally, patients may also minimize their symptoms in efforts to elicit positive and hopeful accounts from clinicians (Evans et al., 2006). This final rationale mirrors the dilemma of wanting to be honest, but not too honest (Hintz, 2019) in which individuals want to share pertinent information but not to the degree that the information may result in negative repercussions or reduce hope. However, incomplete patient information limits clinicians' knowledge and treatment abilities.

Timing of companion participation in medical interactions

NRT describes how communication can be evaluated based on the timing or position of the utterance (Goldsmith, 2019). Utterances can be viewed as helpful or damaging as dependent on their placement within the larger conversation (e.g., Bute, 2009). Companions shared how they developed communicative practices to manage their hesitancy and uncertainty about how and when to participate within medical interactions, and that the most efficacious and appropriate approach to participation included being mindful of the timing of their participation. Medical interactions follow an established organizational structure (Koenig & Robinson, 2014). These structures vary as determined by medical goals; for example, acute care in primary visits follows a different structure than interactions in adjuvant cancer care (Roberts, 1999; Robinson, 2003). However, as companions learned the gynecologic chemotherapy treatment structure, they identified potential opportunities for their participation. Namely, after clinicians act to explore patient wellbeing and solicit patient information, and prior to the closing of the visit, companions could offer their input or make additional inquires. Timing their participation in this fashion allowed companions to accomplish their goals and did not minimize patients' accounts. Participation timing also communicated that patients' accounts are prioritized and companions' accounts are complementary, supporting the patient as central in the interactions.

Practical implications

Evaluation of the emergent themes highlight the tensions inherent in patients' accepting and companions' providing support. Recent research has provided guidelines and strategies for clinicians during triadic interactions (Laidsaar-Powell et al., 2019). For example, clinicians are encouraged to welcome all present, including companions, inquire about patients' and companions' expectations of companion participation, and offer suggestions for appropriate forms of companion support. Study findings how timing and framing is important for companions, and providers could also cue patients and companions of these strategies.

Similar best practices for patients and companions are not yet widely available. Practically, prior to medical interactions, patients and companions should talk about how they want to share and manage communicative roles in the medical interaction and their expectations of how each will participate.

They should establish if both hold similar expectations of a dominant patient and supportive companion, patient and companion as equally participative, or as a passive patient and dominant companion (Street & Gordon, 2008). Further, dyads can discuss shared expectations for companion behavior when companion perceptions differ or if they have questions. Finally, patients and companions should also be counseled on how their behaviors, such as companions speaking for patients or providing contradicting information, can undermine patient identity as autonomous and able or undercut the dyad's relationship as a team working together. Preparing for medical interactions should extend beyond preparing a question list of *what* to ask and should also include attention to ways communicating respect and concern for the patient (Goldsmith & Miller, 2015; Miller & Zook, 1997). Dyads should prepare for medical interactions by contemplating how to communicate in ways support salient identities and relationships (Goldsmith & Miller, 2015; Venetis et al., 2020).

Limitations and future research

Despite the contributions of this research, limitations exist. First, participants include those in which both patients and companions agreed to participate. Thus, these tensions reflect dyads in which both parties were willing to report on their communication; this reflects a generally but not exclusively increased degree of interdependence and closeness. In fact, when asked about the relationship with the other, most reported having very close and strong relationships. As such, the communicative dilemmas that represent communication of less close dyadic partners may extend beyond those described in this manuscript. Second, although a great strength of this research is that data collection occurred while patients underwent treatment, scheduling interviews on days when they were stronger, it represents a limited representation of the entire gynecologic cancer treatment trajectory. Communication dilemmas and tensions may adapt and evolve longitudinally, and future research should examine how these changes occur. These data represent a variety of companions; although emergent themes occurred across relationship type, future research may explore how communication dilemmas may be unique to a subset of dyad types such as spouses or parents with adult children. Another limitation is that the majority of participants were Caucasian, Non-Hispanic, and additional approaches to meaning making, dilemmas, and communicative practices may emerge when other ethnic groups have greater representation within sample. Future research should pursue replication of this research among racial and ethnic minorities to better understand how patients and companions manage companion participation during medical interactions and if the norms described here are consistent across cultural groups. Finally, companions offered communicative practices of how to manage dilemmas when they felt compelled to participate but the patient did not request, want, and/or expect their participation. Companions did not, however, offer communicative practices for managing the dilemma of patient expectation of companion participation that exceeded companion comfort. Thus, future research

should further examine this dilemma and identify approaches to manage such tensions.

Conclusion

This research, framed in NRT, investigates communicative dilemmas that patients and companions experience when companions participate in gynecologic cancer treatment medical interactions. Patients and companions who described working as a team also described a shared expectation of each other's role in the medical interaction. Patients and companions described dilemmas when behaviors did not align with expectations. Patients reported tension when they had anticipated receiving support from others who did not provide it or provided less than anticipated. Further, they reported tensions when companions communicated more than expected or shared information that exceeded what they would like known about them. Companions expressed dilemmas when patients reported that they were "fine" and minimized symptoms. Companions shared communicative practices they developed for managing these tensions. NRT provided a valuable lens to examine these descriptions of medical interactions.

Note

1. The presence of a companion does not generally influence visit length (Street & Gordon, 2008) as unaccompanied patients produce similar utterances as patient and companion dyads (Wolff & Roter, 2011).

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