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# Healthcare provider assessments of caregiver communication behaviors during gynecologic Cancer treatment appointments

Angela Senger a, c, \*, Maria K. Venetis a, Kathryn Greene a, Danielle Catona b, Katie A. Devine c

- a Rutgers, The State University of New Jersey, Department of Communication, 4 Huntington Street, New Brunswick, NJ 08901, USA
- <sup>b</sup> University of Maryland, School of Public Health, 4200 Valley Drive, Suite 2242, College Park, MD 20742-2611, USA
- <sup>c</sup> Rutgers Cancer Institute of New Jersey, Department of Pediatric Population Science, Outcomes, and Disparities Research, 195 Little Albany Street, New Brunswick, NJ 08901. USA

#### ARTICLE INFO

Keywords:
Triadic healthcare visit
Gynecologic cancer
Oncologists
Nurses
Caregivers
Communication

#### ABSTRACT

Objective: Caregivers often accompany patients to cancer-related medical appointments. Limited research exists on healthcare providers' (HCPs) evaluation of how caregiver communication influences interactions between healthcare providers and patients, particularly during gynecologic treatment visits. HCPs may perceive caregiver communication as helpful or challenging, and these triadic interactions may influence patient outcomes.

Methods: Interviews with ten cancer specialist HCPs (medical assistants/technicians, nurse practitioners/registered nurses, oncologists) addressed experiences interacting with patients and caregivers.

Results: Analyses revealed two themes concerning helpful communication: caregivers managing information and managing patient emotions. Three challenging themes include caregiver communication unsettling healthcare interactions, caregiver presence limiting patient communication, and caregiver engagement challenges.

Conclusion: HCPs evaluate caregiver communication as helpful and challenging. Findings suggest benefits of communication training for gynecologic cancer patients such as requesting privacy when interacting with HCPs, for caregivers to promote awareness of effects of their behavior, and for HCPs to help manage triadic interactions while supporting patient needs.

Innovation: HCP assessment of caregiver communication during gynecologic treatment visits offers unique insights regarding helpful and challenging behaviors contributing to implications for patient care and well-being. Applications may extend to other triadic interactions and cancer settings.

#### 1. Introduction

It is common and recommended for family, including spouses, siblings, and adult children, and close friends to accompany cancer patients to healthcare consultations [1,2]. Medical interactions often include healthcare providers (HCP), patients, and caregiving others (henceforth, caregivers), creating minimally triadic rather than dyadic interactions. Caregivers may perform multiple roles in cancer care including transportation, information seeking, managing information sharing in medical interactions, decision-making, and providing emotional support [3-7]. Ample data exist on patient and caregiver perceptions of provider behavior during treatment visits [8] including recommendations for changes in provider communication, especially within geriatric care [9,10]; limited data categorizes patient and partner evaluation of

caregiving behavior in the cancer context [5,11]. Less is known about HCPs' evaluation of how the presence of caregivers influences interaction dynamics during cancer visits. Exceptions include oncologists' perceptions of caregiver behavior [12,13]. This manuscript addresses this gap by examining HCPs' assessments of caregiving communication within gynecologic cancer treatment appointments.

# 1.1. Caregiver participation in cancer healthcare appointments

Individuals undergoing treatment for serious illness like cancer experience increased uncertainty about their health and health decisions, ambiguity about what information or experiences mean, increased emotional strain, and reduced physical capabilities [14,15]. Many individuals managing cancer (henceforth, patients) are

<sup>\*</sup> Corresponding author at: Rutgers, The State University of New Jersey, Department of Communication, 4 Huntington Street, New Brunswick, NJ 08901, USA. E-mail addresses: angela.senger@rutgers.edu (A. Senger), maria.venetis@rutgers.edu (M.K. Venetis), klgreene@rutgers.edu (K. Greene), dcatona@umd.edu (D. Catona), katie.devine@rutgers.edu (K.A. Devine).

accompanied by caregivers that attend to their needs in informal caregiving capacities. Caregivers participate to various degrees, ranging from passive companions, such as a driver and quiet company, to advocates who take notes, ask questions, and actively communicate with HCPs [10,16-18]. A systematic review of triadic provider-patient-caregiver interactions with patients experiencing chronic pain reported that caregivers often influence triadic interactions by asking questions and providing supplemental information [2]. They also support patients with memory aid, participate in decision-making, and serve as interpreters [10,19].

# 1.1.1. Patient and caregiver positive evaluations of caregiving behavior

Patients, and particularly those with higher anxiety, report greater preference for caregiver presence during medical interactions [20]. Patients' most appreciated and requested caregiver behaviors include being present, providing emotional support, and helping with information and appointment logistics [20]. Some patients reported increased efficacy and comfort in sharing information with HCPs when caregivers are present [21].

# 1.1.2. Patient and caregiver negative evaluations of caregiving behavior

Caregiver participation can also be viewed negatively by patients. Caregivers may inhibit information exchange, particularly in regard to challenging topics [2]. Caregivers may also speak for patients when patients are able or may exceed patients' expectations for caregiver participation [22,23]. Other times caregivers dominate and control medical interactions [24]. Thus, certain caregiver behaviors reduce patient engagement. In fact, breast cancer patients asked more questions and interacted more with oncologists when unaccompanied [25]. Similarly, cancer patients disclose less when caregivers are present [17].

#### 1.1.3. HCP evaluations of caregiving behavior

Although research has cataloged how patients and caregivers perceive caregiver behavior, less is known about how HCPs evaluate how caregiving behaviors impact triadic interaction. Physicians view caregivers as supportive and useful when clarifying patient history [1]. Alternatively, oncologists report that family presence during medical interactions can also complicate consultations particularly if caregivers dominate interactions or introduce difficult family dynamics [6,12].

This paper is part of a larger project examining gynecologic cancer patient-caregiver-provider triadic communication during outpatient oncology treatment visits. Specifically, we examine HCP evaluations of how caregiver behaviors benefit or complicate gynecologic treatment appointments, and we ask: what are caregiver behaviors that HCPs evaluate as positive and negative during gynecologic cancer triadic interactions?

#### 2. Methods

#### 2.1. Participants and procedure

Participants (N=10 HCPs) were recruited from an NCI cancer center of excellence in a semi-urban area of the northeastern United States. Inclusion criteria were aged 18 or older, English speaking, regularly in contact with gynecologic cancer patients and their caregivers, and consent to participate and audio-record the interview. Procedures were approved by both the university institutional review board and the hospital's scientific review board. Participants included 10 HCPs who completed audio-recorded telephone interviews. Participants were 9 females and 1 male who described themselves as medical doctors (n=4, 40%), medical assistant/technicians (n=3, 30%), and nurse practitioner/registered nurses (n=3, 30%). See Table 1. Research staff identified and approached 14 HCPs who met target criteria and explained study goals. Five physicians/GYN oncologists, four nurse practitioners and registered nurses, and five medical technicians and medical assistants worked regularly in the clinic/division. Of those who

Table 1 Healthcare providers' demographic characteristics (N = 10).

Characteristic	n	%
Sex		
Female	9	90
Male	1	10
Professional role		
Oncologist (MD)	4	40
Medical assistant/technician	3	30
Nurse practitioner/registered nurse	3	30
Ethnicity		
Caucasian	4	40
Hispanic/Latinx	2	20
Asian	2	20
African American	1	10
Mixed race	1	10
Years in practice		
< 2 years	3	30
3–5 years	1	10
6–10 years	2	20
11–19 years	2	20
> 20 years	2	20
Age (range 27–62)	M = 40.10	SD = 10.05

initially agreed (n=11), 10 (91%) completed the interview. Participants who declined cited lack of time or starting a new position.

#### 2.2. Measures and analyses

Interviewers included three researchers who were trained to conduct interviews following a semi-structured interview guide. Each interviewer completed practice pilot interviews with healthcare providers. After providing consent and completing interviews, participants received a \$100 VISA gift card.

Interviews averaged ranged from 36 to 76 min (M=56 min; SD=12 min). Research team members transcribed, verified, and deindentified interview data, producing single-spaced transcripts that ranged from 12 to 27 pages (M=17.60, SD=5.06). Verbal fillers such "you know" were removed. Theme saturation began at approximately HCP 7 and concluded after 10 participant interviews [see [26]].

Interviewers followed a semi-structured guide consisting of 23 questions and collected information about participant demographics and views on gynecologic cancer triadic interactions. Germane to this study, we asked about HCP perceptions of caregiver behaviors (e.g., "In what ways are caregivers helpful/unhelpful during oncology appointments?"

For the present study, following phases of reflexive thematic analysis [27,28], two research team members independently immersed themselves in the transcribed text to achieve data familiarization. Coders inductively coded three transcripts independently and generated initial codes that identified caregiver behaviors and HCP evaluations of those behaviors. The coders discussed how these codes contribute to broader themes and subthemes, using examples of data to demonstrate themes. Coders generated a thematic map and then again coded the first three transcripts as well as the other seven. Coders met again to review codes, resolve any discrepancies, and define and name themes.

### 3. Results

HCPs described multiple caregiver communication behaviors as helpful or challenging to oncology interactions, overall visit, and patient well-being. *Helpful* behaviors include two themes including caregivers managing patient information and managing patient emotions (see Table 2 for descriptions and additional quotations). HCPs discussed three challenging communication behavior themes: caregiver communication unsettling the healthcare interaction, caregiver presence limiting patient communication, and caregiver engagement challenges (see Table 3 for descriptions and additional quotations).

 Table 2

 Caregiver communication behaviors evaluated by HCPs as helpful.

Theme (2)	Operational definition	Example quotes
Managing information	How HCPs perceive that caregivers manage information during treatment visit	
Subthemes Keeping track of information	Caregivers take notes and serve an administrative function for patients	They'll [caregivers] try to fill in gaps that the patient may not have told me or forgot to tell me" (HCP 3).
Advocating for patient	Caregivers ask follow-up questions and request clarification from HCPs	They [patients] look to their support person for assistance with questions such as "What did I want to ask?" (HCP 4) Sometimes the patient is scared to ask [the] family want to have more knowledge about it." (HCP 7)
Accurately presenting patient symptoms	Caregivers describe patient disease-related symptoms and behaviors to HCPs	They're [adult children] like, 'This is my mom. So, can you tell me what's going on or can you tell me what medications she'll be getting?' (HCP 10) Sometimes they [patients] withhold information from me because they're trying to be brave but then the [patient's] daughter's with her She's like, 'No, she's not eating well, and she has anxiety attacks.' (HCP 3)
		'Listen, I know she [patient] is not going to say it, but she was nauseous, she not eating.' (HCP 6)
Managing emotions	How HCPs perceive caregivers provide emotional support and manage emotions during the treatment visit	
Subthemes Providing emotional support	Caregivers' presence in the visit provides comfort	Just their [caregivers'] physical presence helps the patients open up a little bit or feel safe. (HCP 2)
Protecting patient from worrying	Caregivers subdue their own anxieties in the presence of the patient, at times they seek out HCPs separately for prognosis-related information	Just feeling that you're not alone in this. (HCP 10) They [caregivers] definitely hold back their fears if they're worried themselves. (HCP 8)
		'Well, what do you <u>really</u> think? How much time do you think she has? Is this really going to work?' (HCP 3)

# 3.1. Caregiver communication behaviors evaluated by HCPs as helpful

# 3.1.1. Managing information

HCPs commonly stated that caregivers assisted patients in managing information during visits. "Managing information" includes actions related to information being passed between healthcare providers, patients, and caregivers and what kind of information is being shared with

**Table 3**Caregiver communication behaviors evaluated by HCPs as challenging.

Theme (3)	Operational definition	Example quotes
Caregiver communication unsettling the healthcare interaction	How HCPs perceive caregivers express and enact their own needs regarding the patient's treatment, end-of-life decisions, and symptoms (either against HCP recommendations or patient wishes).	The support person being assertive and
Interfering with HCP's agenda	Caregivers impose their own agenda regarding the patient's treatment, end-of-life decisions, and symptoms.	aggressive, and trying to push for things that the patient doesn't necessarily want. (HCP 3)
Caregiver expressed anxieties increasing patient anxiety	Caregivers' anxious behavior creates stress for the patient.	they [caregivers] can get in the way a little bit of the message that I'm trying to give. (HCP 4) [Caregiver], 'What am I going to do?' It gets
		the patient riled up and stressed. (HCP 10)  The patient was nervous. The friend too. She [caregiver] was panic. She would make the patient more panic. (HCP 6)
Caregiver presence limiting patient communication	How HCPs perceive caregivers have an inhibitory effect on the patient sharing of some topics	
Subthemes Caregiver presence limiting patient expression regarding prognosis	Patients avoid asking HCPs about prognosis if the caregiver is present	When they're [patients] scaredthen they want to ask privately 'What's my prognosis?' (HCP 8)
Caregiver presence limiting patient discussion of sexuality with HCP	Patients avoid discussing disease-related sexual issues with HCP if the caregiver is present	It was so hard, they [caregivers] would not leave her alone. Finally [caregivers were gone] she said, 'I want to die.' (HCP 9) They [patients] want to know if that's [vaginal dryness] going to be an outcome of their treatment. They don't want to talk about it in front of their adult children or their husband. (HCP 8)
		If they're [patients] having pain during intercourse, definitely, they don't want their husbands to hear that. (HCP 9)
Caregiver engagement challenges	How HCPs perceive caregivers either emotionally disengaged in the patient's treatment process or timing of	
Subthemes Disengaged caregiver	telecommunication not optimal  Caregivers do not participate	It's not helpful when they [caregivers] go outside. When they go outside, they don't (continued on next page)

Table 3 (continued)

Theme (3)	Operational definition	Example quotes
	in the patient's treatment visit and do not fulfill support needs	want to be there, because it's a lot of information that the patient has to get And some family members being there to help to get information and digest information, they go outside. That's not helpful. (HCP 7)
Connecting with distanced caregiver	Patients request caregivers' tele-involvement at the end of the visit creating communication challenges	When it gets really bad then they [caregivers] stop coming because it's just too much for them. (HCP 3)
	for HCPs	There at the end [of the visit], [the patient is] like 'Oh, let me call my son. He wants to hear it from you.' So suddenly I have these two people that are calm, they're happy with me, and I have this questioning son that I haven't had any rapport with that [interaction], I don't do well. (HCP 9)

HCPs. Managing information subthemes include caregivers keeping track of information shared during visits, advocating for patients, and accurately presenting patient symptoms.

3.1.1.1. Keeping track of information. Several HCPs noted that caregivers actively keep track of information during visits. One oncologist (HCP 10) described caregivers as "really just being their [patients'] second brain" which is echoed by another oncologist (HCP 9) who reported that "they [caregivers] take notes, they remind the patient, when the patient gets confused with statements such as 'Oh, you didn't tell me that,' they usually step in." An RN (HCP 8) described caregivers as someone patients can "bounce ideas off of ... maybe what their preferences are as far as life choices." One oncologist (HCP 4) explained that the conversations during visits "can be overwhelming for the patients and may confuse them, so they look to their caregiver for assistance with questions such as 'What did I want to ask?'; [caregivers] have their mind clearer than the patient." Examples underscore the important role caregivers have in supportively managing information.

3.1.1.2. Advocating for the patient. HCPs also perceive caregivers to be helpful when asking questions and advocating for patients. A medical technician (HCP 6) noted, "[A]ll the family comes with a lot of questions about the treatments." One oncologist (HCP 4) stated, "I think they're [caregiving friends] there to protect the patient" (HCP 4, oncologist). HCP 8 (RN) shared that a spouse might be more of an advocate "because they're likely living with the person ... seeing all their symptoms and side effects." An oncologist (HCP 10) shared "They're [adult children caregivers] very strong advocates" seeking information about diagnosis and treatment, adding an overall statement about caregivers: "They're [caregivers] really a voice for the patient." HCPs uniformly viewed caregivers taking an active role in information gathering and patient advocacy (e.g., ensuring that all questions are being addressed) as helpful.

3.1.1.3. Accurately presenting patient symptoms. HCPs describe how caregivers provide information about patient symptoms, referring to

them as "a very good reporter" (HCP 10, oncologist). One medical assistant (HCP 1) shared:

The son said everything that she was going through: 'Listen ... she's had some memory loss. She's not really eating right; she's not getting around like she used to. She spends more time in the bed.' So those are things that she [the patient] was not saying.

HCPs rely on caregivers to give them "an accurate report of what's going on at home, as far as symptoms and side effects" (HCP 8, RN). A nurse practitioner (HCP 5) stated, "I can ask the patient a question, and they'll say, 'Oh, so-and-so,' and whomever is with the patient will be like, 'No, that's not true. No, that's not accurate.' Then they'll tell me what the real story is," thus providing oncology teams with information that patients might not have volunteered but might be of medical importance. Caregivers sharing patient symptoms might cause disagreements between patients and caregivers, but HCPs view this behavior positively, "... it's good, because then I'll be like to the daughter or husband, 'What's really going on?' ... And trying to help them [caregivers] be better support" (HCP 3, oncologist).

Some of this "accurate" information is not always shared in the patients' presence. Caregivers may seek out HCPs separately from patients, often in the hallway. At times, this occurs to avoid conflicts with patients. A medical assistant (HCP 7) related:

The family support said, 'My mom is not eating, but don't tell her [doctor] in front of her [patient] because I don't want to argue with my mother, so just tell the doctor that she's not eating.' So, I tell the doctor, and the doctor says, 'Oh, I see you lost a lot of weight. I wonder why you lost a lot of weight?'

Caregivers want HCPs to receive accurate information about patient disease-related behavior at home.

#### 3.1.2. Managing emotions

HCPs perceive caregivers managing patients' emotions as helpful. Subthemes included providing emotional support and protecting patients from worrying.

3.1.2.1. Providing emotional support. HCPs commented how caregiver presence is calming and helpful. Often, having caregivers in the room has a calming effect on patients and provides "emotional support for sure" (HCP 8, RN). A medical assistant (HCP 7) stated, "I think they [caregivers] are helpful ... Sometimes they [caregivers] don't even say nothing. They stay quiet. But it's just knowing that you have somebody there." One oncologist (HCP 9) shared, "I find them [caregivers] useful with patients when they [patients] get a little belligerent because they're scared, they calm them down. So, I don't have to. Usually, they [caregivers] come to my rescue." Another oncologist (HCP 10) mentioned the difficult situation when patients receive troubling diagnoses and "having family nearby ... I think is a really huge role. Even if you're not doing anything, just being there physically just helps."

3.1.2.2. Protecting the patient from worrying. HCPs described another helpful behavior of how caregivers conceal their own anxiety to protect patients from worrying. HCPs reported that caregivers "hold[ing] back in front of the patient" (HCP 3, oncologist). An RN (HCP 8) shared that caregivers say, "Is there any way I could talk to you and the doctor alone?' ... They want to talk to somebody about their fear but they're not verbalizing it in front of the patient." Caregivers may want to receive an honest assessment of the patient's prognosis without burdening the patient with this information: "Is she going to die, soon?" You know, that's very common. They [caregivers] don't want them [patients] to know that they're asking" (HCP 9, oncologist). Another oncologist (HCP 10) related, "the support team [family] was like 'She can't handle the information right now. Can we talk about it separately? Do I take them [patient] home for home hospice?" These examples illustrate the

A. Senger et al. PEC Innovation 4 (2024) 100259

caregivers' concern for the patient's wellbeing and the protective role they have during these visits.

# 3.2. Caregiver communication behaviors evaluated by HCPs as challenging

#### 3.2.1. Caregiver communication unsettling the healthcare interaction

HCPs described two scenarios in which caregiver communication was challenging when it contradicted the HCP agenda or, at times, patient wishes, and when caregivers' sharing of their own anxieties upset patients.

3.2.1.1. Interfering with HCP's agenda. HCPs described how some caregivers attempt to exert influence over treatments or push for the continuation of treatment against the patient's preference and—at times—against medical recommendations. A medical assistant (HCP 1) shared how patients are "taking their doctor's advice," yet caregivers repeatedly ask patients, "Don't you think you should get a second opinion?" Caregivers may inhibit care by imposing ideas about treatment and actively going against treatment recommendations. One oncologist (HCP 3) described:

There's certain people with certain personalities that are like 'No, you need to talk to *me*.' Or 'This is ... my wife or my mom, and this is what I want done.' ... I have this patient ... I told her 'You need immunotherapy', and her son was like, 'No, you need chemotherapy.' He was swaying here. ... He was a roadblock in her care. ... She was like, 'No, I just want to do what the doctor says,' and he was like, 'No.'

These types of conflictual discussions also include whether to have *any* treatment: "Sometimes there is disagreement when the patient ... doesn't like interventions, doesn't like medication... And the family ... especially the children ... are a little more feisty about it, verbal and upset about it" (HCP 9, oncologist). End-of-life discussions are particularly challenging as one oncologist (HCP 10) described, "patients usually know when they're about to be done," continuing:

A patient is very sick, and she was on treatment after treatment. As a provider ... what they're going through ... it was unwise to continue treatment.... But the spouse was very against ... stopping treatment because it would mean that she was going to die soon, and he could not handle that. ... You could tell the patient was OK with it.

These types of interactions can be difficult to manage and may require HCP engagement. One oncologist (HCP 3) described the role of HCPs as that of a "referee" and explained that it is about "getting everyone on the same page ... refocusing people's focus."

Conversations that involve symptoms can create tensions. One oncologist (HCP 4) described discussing patients' eating, a common "topic of stress" between caregiver and patient:

[Caregiver:] 'She needs to eat more. She's losing weight.' The patients usually are quiet during that time. ... When I tell them [caregivers], 'Your mom ... either doesn't have an appetite or when she eats, she gets full very quickly.' And the patient wakes up from her silence and goes 'You see? Listen to the doctor.'

Caregiver interference with HCPs' agendas can be more subtle such as mis/reinterpreting or downplaying oncologists' messages in unhelpful ways:

A lot of the time we say things, and the caregiver just changes what we're saying to make it softer and sometimes different than what we just said. ... Sometimes ... the caregiver jumps in and says things like, 'Yes, but everything is going to be OK,' when I just told them ... 'Maybe you have one month to live.' (HCP 4, oncologist).

Caregivers interfering with HCPs' treatment recommendations,

symptom management, and at times reinterpreting medical statements creates challenging situations for HCPs, requiring skillful communication while navigating such interactions.

3.2.1.2. Caregiver expressed anxieties increasing patient anxiety. HCPs reported that caregivers can cause anxiety and stress in patients by expressing their own anxieties. An oncologist (HCP 9) observed "These two sisters [patient and sister], one feeds the other's anxiety." Another oncologist (HCP 10) noted:

They're [caregivers] like, "What are we going to do?" ... And it fuels a patient, too ... The family member keeps on being, "This is not fair, what's going on?" ... It's not really helping the whole situation when it's out of everybody's control.

This is echoed by a medical technician who observed that when patients arrive with anxious caregivers, "That doesn't help at all," describing a particular incident where "she [caregiver] was really anxious with a lot of questions, 'I read this. I read that.' And then she would make the patient panic" (HCP 6). A registered nurse (HCP 8) added to this observation by noting that "giving their [caregivers] own personal opinion of a medication, treatment or oftentimes a story of a bad experience they had in a hospital or a surgery or with a medication, that might be causing more fear than support." Sharing of negative experiences by caregivers heightens patients' stress levels and increases their anxiety.

# 3.2.2. Caregiver presence limiting patient communication

Caregivers can have an inhibitory effect on patients' self-expression, especially with sensitive topics such as subthemes described for prognosis and sexuality.

3.2.2.1. Caregiver presence limiting patient expression regarding prognosis. When discussing prognosis and end of life, patients sometimes want to be alone with HCPs. An RN (HCP 8) reported, "Fear of an unsuccessful outcome is a thing ... that they [patients] don't share if there's another close family member [present] ... I get that information more if I'm alone with them or the doctor's alone with them." An oncologist (HCP 9) emphasized this point:

She [patient] would become very submissive when the sons and husband were there that wanted us to do everything for her. But there was really nothing to do. ... It was so hard, they [caregivers] would not leave her alone. Finally, they [caregivers] were gone, and ... she said, 'I want to die.'

Despite these challenges, one oncologist (HCP 3) stated, "not tell [ing] family members, ... I think it's just wrong ... and can be very isolating and make your treatments ... so much harder." These examples highlight the need for HCPs to consider patient preferences when discussing prognosis and end-of-life in the presence of caregivers.

3.2.2.2. Caregiver presence limiting patient discussion of sexuality with HCP. Sexuality and changes to patients' bodies due to treatment may be another topic that patients prefer to express when alone with HCPs. A medical assistant (HCP 1) described:

For this visit, she came in by herself, and she was saying that she's not feeling the same way sexually ... She just doesn't enjoy it. They'll [patients] tell us that their marriage hasn't been the same since surgery. They lack ... desire to be sexually active. ... It does cause a strain on the relationship sometimes.

An oncologist (HCP 4) observed that patients have difficulty expressing concerns related to their sexual life in front of caregivers, "... because of the treatments and surgeries ... they might have some scarring, pain; and when those symptoms are affecting their sexual drive or intercourse ... that might be a little more difficult for them to share."

This is echoed by a nurse practitioner (HCP 2) who stated: "After surgery, ... they [patients] have side effects with dryness or decreased libido, and a lot of times they don't want to talk about it in front of their significant other because of being embarrassed." Another oncologist (HCP 9) related:

Now, if the husband is there and they want to know about having sex or not. ... Some of them [patients] ask with the husband there, but then the husband gets embarrassed, and the majority ask when the husband is *not* present ... Or if they're having pain during intercourse, definitely, they don't want their husbands to hear that. ... If they're married and it's the kids who are there, they usually don't want to have the kids there when they talk about it.

HCPs expressed the importance of recognizing that patients may provide inaccurate or incomplete information because caregivers are present: "I had one patient ... Her husband was there, and I was asking some GYN questions ... and she was like, 'Oh, I don't remember.' You know, she look[ed] at me, and I knew [she did not want to discuss it in front of her husband]" (HCP 6, medical technician). An oncologist (HCP 3) shared how patients wait until husbands leave the [examination] room, "and then they say, 'You know, I'm really worried about this' or 'This is really affecting my quality of life.'" These exemplars demonstrate how patients may prefer to discuss sexuality-related topics without caregivers present.

#### 3.2.3. Caregiver engagement challenges

HCPs described two scenarios centered on degrees of caregiver engagement as challenging. These include when caregivers are present but non-participative and when caregivers are absent, but patients request HCP communication with caregivers at the end of the interaction.

*3.2.3.1. Disengaged caregiver.* HCPs perceived healthcare interactions as challenging and unhelpful when caregivers leave during the visit or do not join the patient, viewing this behavior as disengaged. A medical assistant (HCP 7) provided an example:

I feel like they [caregivers] don't even want to be there sometimes. ... I see some daughters with mothers; they bring the mother, and they want to stay outside. And the mother says, "No, you can come and stay with me in the room," and the daughter says, "No, I'd rather be outside because I feel better being outside." That's not helpful.

An oncologist (HCP 9) also expressed that disengaged caregivers are "unnerving ... because I need to establish rapport with the support system. ... I'm trying to figure where the problems are, what's getting her anxious, what's worrying her, or what did she understand or not." When caregivers are not present or are disengaged, they cannot provide additional information that might be useful. Being disengaged can also be a sign of caregiver burden. One oncologist (HCP 3) alluded to the stress that can affect engagement, "when it gets really bad then they [caregivers] stop coming because it's just too much for them ... They can't take it anymore and they don't want to hear any more bad news." Overall, HCPs accentuate uninvolved behavior of caregivers as unhelpful support behavior.

3.2.3.2. Connecting with distanced caregiver. HCPs described challenges when engaging with distanced caregivers that include use of technology as well as timing of inclusion. One oncologist (HCP 9) described that telecommunication with invested family and friends can be "tricky because we're not used to it. ... So, it's something new ... but is happening more." HCPs also described challenging moments when patient's children want to engage in support but are not present, perhaps due to geographic distance. The same oncologist (HCP 9) explained:

They were not in the process of this visit where I calm everybody down. There at the end [of the visit], [the patient is] like 'Oh, let me

call my son. He wants to hear it from you.' So suddenly I have these two people that are calm, they're happy with me, and I have this questioning son or daughter that I haven't had any rapport with ... that [interaction], I don't do well.

These exemplars demonstrate how requesting tele-health connections with caregivers during medical interactions can disrupt the medical interaction and can be viewed as challenging.

# 4. Discussion and conclusion

#### 4.1. Discussion

Caregivers often accompany patients to oncology treatment visits, indirectly or directly influencing the HCP-patient interaction. Research exploring these triadic consultations with patients, their caregivers, and different types of gynecologic HCPs is limited. This study sought to understand how oncologists, nurses, and medical technicians experience these interactions, specifically exploring HCPs' perceptions of caregiver behaviors as helpful and/or challenging.

Literature emphasizes *helpful* functions of caregivers [29], which were also raised by HCPs in this study. Aligned with research, HCPs perceived caregivers as helpful when managing information [30] and managing emotions [31]. Yet, much of this prior literature is not from the HCP perspective; for exceptions see Laidsaar-Powell and colleagues [13,29].

HCPs also consistently raised challenging caregiver behaviors. Findings support prior research and identify that caregiver behaviors present interaction challenges for HCPs when caregivers interfere with the HCP's agenda and when their presence inhibits patient disclosure regarding prognosis or sexuality [32,33]. Additionally supporting prior work, unhelpful behavior HCPs discussed most is interference with treatment decisions, including what treatment to pursue or when to stop treatment [34,35]. Findings also extend prior research: specifically, HCPs evaluated caregiver behaviors as challenging when caregivers express their own anxieties, when caregivers are disengaged, and when patients request caregiver inclusion via telehealth.

Some caregiver behaviors might not be viewed uniformly. For example, accurately presenting patient symptoms, categorized as helpful support behavior because it allows HCPs to have a more accurate picture of symptoms, behavior, and quality of life (QOL), may contrast with the patient's expectation of caregiver behavior and cause tension [23]. If patients feel spoken over and not validated by caregivers, they may feel they have lost their voice. Oncologists should be cognizant of this potential for tension, a finding that echoes caregiver perspectives of tensions in managing accompanying patients [36,37].

Consistent with research in gynecologic settings, findings indicate that HCPs notice how patients avoid discussing certain topics when caregivers are present [38]. Topics such as prognosis and sexual functioning can inhibit patient expression, making it more difficult for HCPs to discuss when caregivers are present. For gynecologic cancer patients, discussing sexual activity or lack thereof after cancer treatment and/or associated concerns or issues in this realm, such as dryness, pain, etc. with their HCP in the presence of a caregiver is especially challenging. Being sensitive to patients' potential need for privacy or desire to speak to HCPs alone in this matter, is critical for HCPs. Similarly, spouses might want to speak with HCPs about their sexual concerns without patients present. At times, both caregivers and patients prefer to speak with HCPs alone about sensitive issues related to gynecologic cancer and its aftereffects. This might also vary culturally and requires further exploration. These data suggest that HCPs should offer patients the option to speak alone; similarly, HCPs should be cognizant of caregiver concerns.

#### 4.2. Innovation

Previous studies have examined triadic patient-caregiver-provider communication in the cancer context predominantly evaluating HCP communication. This study highlights HCPs' perceptions of caregiver behavior during gynecologic cancer treatment visits which can be both helpful and challenging in achieving HCP interaction goals, healthcare decisions, and patient well-being. Findings also offer unique insights to HCP evaluations of how caregiver presence may inhibit patient disclosure.

Managing triadic interactions including navigating conflicting interests among patients and caregivers is challenging for HCPs. Communication training for HCPs, patients, and caregivers delineating what is helpful and creates tensions and teaching specific communication strategies could mitigate some of these challenges [36]. Training recommendations for oncologists include involving caregivers, emphasizing helpful behaviors, and discussing patients' and caregivers' roles to avoid conflict [36]. Educational modules specifically for caregivers may better meet their informational needs and increase the likelihood of patient satisfaction and positive clinical outcomes [37].

Existing communication trainings for HCPs, such as Communication Skills Training Program and Research Laboratory [39] include modules specific to managing caregiver presence. Studies highlight the need to positively influence patient-spouse communication to reduce conflict and enhance dyadic congruence, especially germane to intimacy [30,40]. Other programs address caregiver needs. For example, the VOICE study facilitates communication about prognosis and healthcare decision making among oncologists, caregivers, and patients with advanced cancer [41,42] and demonstrates that HCPs can enhance patient and caregiver engagement during oncology visits via "partnershipbuilding and supportive talk" [43]. Additionally, HCPs discussing emotional consequences of treatment options with patients and caregivers is important [44]. Research recommends regularly including nurses and health educators in triadic treatment visits to "continue discussions as needed" [45], as most training to date is limited to physicians.

Limitations of this study include that this study examined support at a particular time in treatment and may not inform how caregiver behaviors might change over time [46]. Also, the study sample was small, limiting the ability to compare if differences exist across different types of providers. Future research should replicate across illness conditions to determine if caregiver behaviors are similarly evaluated in other health contexts.

#### 4.3. Conclusion

HCPs evaluate caregiver communication as both helpful and challenging. Helpful behaviors outlined in these data elucidate the vital role of caregivers accompanying patients to oncology visits. Simultaneously, there are opportunities to improve these triadic interactions and address some behaviors and their influence during treatment interactions. Additionally, oncologists might also want to utilize the caregiver's role when indicated as a "therapeutic lever" to improve patients' QOL versus solely focusing on the patient's survival [38] and acknowledge caregivers' unique role [47]. Future research may assess relational quality between patients and caregivers and how relational quality impacts caregiver behaviors.

Future research is needed to delineate challenges due to communication modes (e.g., phone or videoconference). Telemedicine is increasing in oncology [48], and HCPs may be supported with training tailored to guide caregivers who are unable to attend visits in person [36]. Several HCPs (oncologists specifically) raised this as a common challenge. HCPs are encouraged to communicate in supportive and caring ways particularly while interacting digitally [35]. Future research should also evaluate efficacy of communication training for patients, caregivers, and HCPs. Patients may benefit from training that

educates them on requesting time alone with HCPs. Caregivers may benefit from learning helpful communication strategies during medical interactions including asking for time alone with HCPs should they desire privacy and how to manage potential sources of caregiver burden. HCP training can center on navigating conflict between patients and caregivers, facilitating caregiver engagement during triadic interactions, managing caregiver telecommunication during healthcare interactions, and sensitivity to caregiver concerns.

#### **Funding**

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

#### CRediT authorship contribution statement

Angela Senger: Conceptualization, Formal analysis, Writing – original draft, Writing – review & editing. Maria K. Venetis: Data curation, Formal analysis, Supervision, Writing – original draft, Writing – review & editing. Kathryn Greene: Conceptualization, Data curation, Formal analysis, Methodology, Writing – original draft. Danielle Catona: Data curation, Methodology, Project administration. Katie A. Devine: Supervision.

#### **Declaration of competing interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

#### Acknowledgments

The authors would like to acknowledge the contributions of Dr. Maria Checton, Kristine Levonyan-Radloff, and multiple research assistants to this project.

#### References

- [1] Schilling LM, et al. The third person in the room: frequency, role, and influence of companions during primary care medical encounters. J Fam Pract Aug. 2002;51 (8):685–90.
- [2] Troy E, Doltani D, Harmon D. The role of a companion attending consultations with the patient. A systematic review. Ir J Med Sci 1971 Aug. 2019;188(3):743–50. https://doi.org/10.1007/s11845-018-1920-0.
- [3] Bybee SG, et al. Cancer caregivers at the end-of-life: how much me vs. how much we? PEC Innov Dec. 2023;3:100193. https://doi.org/10.1016/j. pecing 2023 100193
- [4] Chou AF, Stewart SL, Wild RC, Bloom JR. Social support and survival in young women with breast carcinoma. Psychooncology. 2012;21(2):125–33. https://doi. org/10.1002/pon.1863.
- [5] Laidsaar-Powell R, Butow P, Bu S, Fisher A, Juraskova I. Attitudes and experiences of family involvement in cancer consultations: a qualitative exploration of patient and family member perspectives. Support Care Cancer Oct. 2016;24(10):4131–40. https://doi.org/10.1007/s00520-016-3237-8.
- [6] Speice J, et al. Involving family members in cancer care: focus group considerations of patients and oncological providers. Psychooncology. 2000;9(2): 101–12. https://doi.org/10.1002/(SICI)1099-1611(200003/04)9:2<101::AID-PON435>3.0.CO;2-D.
- [7] Vasquez TS, Bylund CL, Fisher CL, Paige SR. Validation of the transactional eHealth literacy instrument with cancer caregivers. PEC Innov Dec. 2022;1:100075. https://doi.org/10.1016/j.pecinn.2022.100075.
- [8] Zachariae R, Pedersen CG, Jensen AB, Ehrnrooth E, Rossen PB, von der Maase H. Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy, and perceived control over the disease. Br J Cancer Mar. 2003;vol. 88(5). https://doi.org/10.1038/si.bic.6600798. Art. no. 5.
- [9] Clayman ML, Roter D, Wissow LS, Bandeen-Roche K. Autonomy-related behaviors of patient companions and their effect on decision-making activity in geriatric primary care visits. Soc Sci Med Apr. 2005;60(7):1583–91. https://doi.org/ 10.1016/i.socscimed.2004.08.004.
- [10] Ellingson LL. The roles of companions in geriatric patient-interdisciplinary oncology team interactions. J Aging Stud Nov. 2002;16(4):361–82. https://doi. org/10.1016/S0890-4065(02)00071-3.
- [11] Manne SL, Ostroff J, Winkel G, Grana G, Fox K. Partner unsupportive responses, avoidant coping, and distress among women with early stage breast cancer: patient

- and partner perspectives. Health Psychol Off J Div Health Psychol Am Psychol Assoc Nov. 2005;24(6):635–41. https://doi.org/10.1037/0278-6133.24.6.635.
- [12] Beisecker AE, Moore WP. Oncologists' perceptions of the effects of Cancer Patients' companions on physician-patient interactions. J Psychosoc Oncol Jul. 1994;12 (1–2):23–39. https://doi.org/10.1300/J077V12N01\_02.
- [13] Laidsaar-Powell R, Butow P, Bu S, Fisher A, Juraskova I. Oncologists' and oncology nurses' attitudes and practices towards family involvement in cancer consultations. Eur J Cancer Care (Engl) 2017;26(1):e12470. https://doi.org/10.1111/ecc.12470.
- [14] Corbeil A, Laizner AM, Hunter P, Hutchison N. The experience of uncertainty in young adults with Cancer. Cancer Nurs Oct. 2009;32(5):E17. https://doi.org/ 10.1097/NCC.0b013e3181a5690d.
- [15] Guan T, Santacroce SJ, Chen D-G, Song L. Illness uncertainty, coping, and quality of life among patients with prostate cancer. Psychooncology. 2020;29(6):1019–25. https://doi.org/10.1002/pon.5372.
- [16] Beisecker AE, Brecheisen MA, Ashworth J, Hayes J. Perceptions of the role of Cancer Patients' companions during medical appointments. J Psychosoc Oncol Dec. 1996;14(4):29–45. https://doi.org/10.1300/J077v14n04\_03.
- [17] Isenberg SR, et al. Family companions' involvement during pre-surgical consent visits for major cancer surgery and its relationship to visit communication and satisfaction. Patient Educ Couns Jun. 2018;101(6):1066-74. https://doi.org/ 10.1016/j.pre.2019.01.011.
- [18] Wolff JL, Roter DL. Family presence in routine medical visits: a meta-analytical review. Soc Sci Med Mar. 2011;72(6):823–31. https://doi.org/10.1016/j. socscimed 2011.01.015
- [19] Veenstra CM, Wallner LP, Abrahamse PH, Janz NK, Katz SJ, Hawley ST. Understanding the engagement of key decision support persons in patient decision making around breast cancer treatment. Cancer 2019;125(10):1709–16. https:// doi.org/10.1002/encr.31956.
- [20] Korotkin BD, Hoerger M, Voorhees S, Allen CO, Robinson WR, Duberstein PR. Social support in cancer: how do patients want us to help? J Psychosoc Oncol 2019; 37(6):699–712. https://doi.org/10.1080/07347332.2019.1580331.
- [21] Ishikawa H, Roter DL, Yamazaki Y, Hashimoto H, Yano E. Patients' perceptions of visit companions' helpfulness during Japanese geriatric medical visits. Patient Educ Couns Apr. 2006;61(1):80-6. https://doi.org/10.1016/j.pec.2005.02.010.
- [22] Mazer BL, Cameron RA, DeLuca JM, Mohile SG, Epstein RM. Speaking-for and speaking-as: Pseudo-surrogacy in physician–patient–companion medical encounters about advanced cancer. Patient Educ Couns Jul. 2014;96(1):36–42. https://doi.org/10.1016/j.pec.2014.05.001.
- [23] Venetis MK, Bontempo AC, Catona D, Buckley de Meritens A, Devine KA, Greene K. Dilemmas and strategy when companion participation during appointments differs from patient and companion expectations. Health Commun 2023;0(0):1–12. https://doi.org/10.1080/10410236.2023.2190244.
- [24] Laidsaar-Powell RC, et al. Physician–patient–companion communication and decision-making: a systematic review of triadic medical consultations. Patient Educ Couns Apr. 2013;91(1):3–13. https://doi.org/10.1016/j.pec.2012.11.007.
- [25] Buizza C, et al. Does being accompanied make a difference in communication during breast cancer consultations? Results from a multi-centered randomized controlled trial. J Psychosoc Oncol Mar. 2021;39(2):189–203. https://doi.org/ 10.1080/07347332.2020.1829775.
- [26] Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: a systematic review of empirical tests. Soc Sci Med Jan 2022;292(114523). https:// doi.org/10.1016/j.socscimed.2021.114523.
- [27] Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3 (2):77–101. https://doi.org/10.1191/1478088706000630a.
- [28] Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qual Res Sport Exerc Health 2019;11(4):589–97. https://doi.org/10.1080/2159676X.2019.1628806.
- [29] Laidsaar-Powell R, Butow P, Boyle F, Juraskova I. Managing challenging interactions with family caregivers in the cancer setting: guidelines for clinicians (TRIO Guidelines-2). Patient Educ Couns Jun. 2018;101(6):983–94. https://doi. org/10.1016/j.pec.2018.01.020.
- [30] Shin JY, et al. Patient-family communication mediates the relation between family hardiness and caregiver positivity: exploring the moderating role of caregiver depression and anxiety. J Psychosoc Oncol 2019;37(5):557–72. https://doi.org/ 10.1080/07347332.2019.1566808.

- [31] Del Piccolo L, et al. Asking questions during breast cancer consultations: does being alone or being accompanied make a difference? Eur J Oncol Nurs Off J Eur Oncol Nurs Soc Jun. 2014;18(3):299–304. https://doi.org/10.1016/j.ejon.2014.02.001.
- [32] Checton MG, et al. Reports of sharing and withholding Cancer-related information by patients with gynecologic Cancer and their supporters. Oncol Nurs Forum Nov. 2019;46(6):676–85. https://doi.org/10.1188/19.ONF.676-685.
- [33] Tetteh DA, Akhther N. Openness and topic avoidance in interpersonal communication about ovarian cancer: an uncertainty management perspective. Qual Res Med Healthc Dec. 2021;5(3):9376. https://doi.org/10.4081/ qrmh.2021.9376.
- [34] Blackler L. Compromised autonomy: when families pressure patients to change their wishes. J Hosp Palliat Nurs Aug. 2016;18(4):184. https://doi.org/10.1097/ NJH.000000000000264.
- [35] Meluch AL. Above and beyond: an exploratory study of breast cancer patient accounts of healthcare provider information-giving practices and informational support. Qual Res Med Healthc Aug. 2018;vol. 2(2). https://doi.org/10.4081/ grmh.2018.7387. Art. no. 2.
- [36] Banerjee SC, et al. Communicating effectively via tele-oncology (Comskil TeleOnc): a guide for best practices for communication skills in virtual Cancer care. J Cancer Educ Off J Am Assoc Cancer Educ Oct. 2022;37(5):1343–8. https://doi.org/ 10.1007/s13187-021-01959-7
- [37] Petronio S, Sargent J, Andea L, Reganis P, Cichocki D. Family and friends as healthcare advocates: dilemmas of confidentiality and privacy. J Soc Pers Relatsh Feb. 2004;21(1):33–52. https://doi.org/10.1177/0265407504039838.
- [38] Orri M, et al. Crossing the perspectives of patients, families, and physicians on cancer treatment: a qualitative study. Oncotarget Mar. 2017;8(13):22113–22. https://doi.org/10.18632/oncotarget.12770.
- [39] Bylund CL, Brown RF, Bialer PA, Levin TT, Lubrano di Ciccone B, Kissane DW. Developing and implementing an advanced communication training program in oncology at a comprehensive cancer center. J Cancer Educ Off J Am Assoc Cancer Educ Dec. 2011;26(4):604–11. https://doi.org/10.1007/s13187-011-0226-y.
- [40] Martinez YC, Ellington L, Vadaparampil ST, Heyman RE, Reblin M. Concordance of cancer related concerns among advanced cancer patient-spouse caregiver dyads. J Psychosoc Oncol Mar. 2020;38(2):143–55. https://doi.org/10.1080/ 073473232011.1644295.
- [41] Epstein RM, et al. Effect of a patient-centered communication intervention on oncologist-patient communication, quality of life, and health care utilization in advanced Cancer: the VOICE randomized clinical trial. JAMA Oncol 2017 Jan;3(1): 92–100. https://doi.org/10.1001/jamaoncol.2016.4373.
- [42] Hoerger M, et al. Values and options in cancer care (VOICE): study design and rationale for a patient-centered communication and decision-making intervention for physicians, patients with advanced cancer, and their caregivers. BMC Cancer Apr. 2013;13:188. https://doi.org/10.1186/1471-2407-13-188.
- [43] Freytag J, et al. The ecology of patient and caregiver participation in consultations involving advanced cancer. Psychooncology. Jun. 2018;27(6):1642–9. https://doi. org/10.1002/pop.4710.
- [44] Perry LM, Hoerger M, Korotkin BD, Duberstein PR. Perceived importance of affective forecasting in cancer treatment decision making. J Psychosoc Oncol Nov. 2020;38(6):687–701. https://doi.org/10.1080/07347332.2020.1768198.
- [45] Eggly S, et al. Development of a question prompt list as a communication intervention to reduce racial disparities in Cancer treatment. J Cancer Educ Off J Am Assoc Cancer Educ Jun. 2013;28(2):282–9. https://doi.org/10.1007/s13187-013.0456-2
- [46] Arora NK, Finney Rutten LJ, Gustafson DH, Moser R, Hawkins RP. Perceived helpfulness and impact of social support provided by family, friends, and health care providers to women newly diagnosed with breast cancer. Psychooncology. 2007 May;16(5):474–86. https://doi.org/10.1002/pon.1084.
- [47] Washington KT, et al. Family caregivers' perspectives on communication with cancer care providers. J Psychosoc Oncol 2019;37(6):777–90. https://doi.org/ 10.1080/07347332.2019.1624674.
- [48] Worster B, Swartz K. Telemedicine and palliative care: an increasing role in supportive oncology. Curr Oncol Rep Jun. 2017;19(6):37. https://doi.org/ 10.1007/s11912-017-0600-y.