

Clinician-patient communication about cancer treatment misinformation: The Misinformation Response Model

M. Devyn Mullis^a, Carla L. Fisher^a, Sklyer B. Johnson^b, Tianshi Liu^c, Tithi B. Amin^a, Sherise Rogers^c, Kennan DeGruccio^a, Carma L. Bylund^{a,*}

^a Department of Health Outcomes & Biomedical Informatics, College of Medicine, University of Florida, 2004 Mowry Road, Gainesville, FL 32610, United States of America

^b Department of Radiation Oncology, School of Medicine, University of Utah, 30 N 19000 E, Salt Lake City, UT 84132, United States of America

^c Division of Hematology/Oncology, Department of Medicine, University of Florida, 1600 SW Archer Road, Gainesville, FL 32610, United States of America

ARTICLE INFO

Keywords:

Physician-patient communication
Cancer treatment misinformation
Patient education

ABSTRACT

Objective: Cancer treatment misinformation (CTM) is pervasive and impacts patient health outcomes. Cancer clinicians play an essential role in addressing CTM. We previously identified four self-reported responses that characterize the communication process clinicians engage in to address CTM. Clinicians 1) work to understand the misinformation; 2) correct the misinformation through education; 3) advise about future online searches; and 4) preserve the clinician-patient relationship. We sought to confirm and expand on the model we developed by observing cancer clinicians' communication while addressing CTM with a standardized patient (SP).

Methods: 17 cancer clinicians were audio recorded in a SP encounter, in which a breast cancer SP asked three questions based on CTM. We thematically analyzed transcriptions of the recordings.

Results: Clinicians used four responses with associated strategies and skills to address CTM in a standardized clinical encounter, confirming the previously developed model. The four responses were: (1) work to understand the misinformation; (2) correct the misinformation through education; (3) advise about future online searches; and (4) preserve the clinician-patient relationship. This observational approach allowed us to refine strategies within each response and identify communication skills clinicians enact to address CTM.

Conclusion: These findings provide a strong foundation for the Misinformation Response Model for cancer clinicians. Future research should examine which components of the model are most effective in improving patient outcomes.

Innovation: This is the first study observing clinicians' communication through simulated practice with SPs about CTM.

1. Introduction

Up to 83% of cancer patients are exposed to cancer treatment misinformation (CTM) [1], defined as including recommendations to pursue unproven/disproven cancer treatments, forego recommended conventional cancer treatments, and buy into myths or misconceptions that could directly or indirectly impact cancer treatment [2,3]. CTM is prevalent on social media and contains both inaccurate and harmful content [2]. Health misinformation acceptance can negatively impact psychosocial outcomes [4-7] as well as evidence-based treatment

acceptance and adherence [4,8]. Prior research has shown that when CTM is accepted and results in refusal of evidence-based conventional cancer treatments like surgery, chemotherapy, hormone therapy, and radiation, mortality is increased by 2.0-2.5-fold, and as much as nearly six-fold depending on the type of cancer, compared to patients who follow recommendations of oncologists [9,10].

Patient-centered communication maximizes the benefits of scientific advancements and medical discoveries. Following a cancer diagnosis, patients experience uncertainty and emotional distress [11,12]. They also need to make difficult decisions related to their cancer treatment.

* Corresponding author at: Department of Health Outcomes & Biomedical Informatics, University of Florida, PO Box 100177, Gainesville, FL 32610.

E-mail address: carma.bylund@ufl.edu (C.L. Bylund).

¹ Carma L. Bylund (Editor in Chief and co-Editor of this special issue) and Sklyer B. Johnson (co-Editor of this special issue) had no involvement in the peer-review of this article and have no access to information regarding its peer-review. Full responsibility for the editorial process for this article was delegated to Nanon Labrie.

<https://doi.org/10.1016/j.pecinn.2024.100319>

Received 22 December 2023; Received in revised form 5 June 2024; Accepted 3 July 2024

Available online 6 July 2024

2772-6282/© 2024 Published by Elsevier B.V. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Effective patient-centered communication can impact important health outcomes [8,12]. Existing research supports the potential for oncologists to play an essential role in addressing CTM based on patients' trust in physicians and the demonstrated impacts of communication on patient outcomes. Repeatedly, studies show that physicians are the most trusted source of information for cancer patients and their caregivers [13-18], more trusted than online sources, family and friends, media, and organizations. Patients' trust in their physicians for cancer information may explain why cancer patients ask their physicians about CTM. Indeed, as Peterson et al. concluded, "oncologists can use their trustworthiness to steer [patients] toward therapy that is evidence-based [19]."

To improve clinician-patient communication about cancer treatment misinformation, we must first explore how clinicians respond to CTM. As part of this effort, we conducted an interview study with 21 cancer clinicians about how they respond to patients about misinformation that they have read online [20]. From this data, we identified an initial typology of clinicians' misinformation responses, which informed an initial communication process model. Clinicians described four responses and associated communication strategies with each response. Three responses were described sequentially: the clinician works to 1) understand the misinformation, 2) correct the misinformation, and 3) advise about future online searches. The fourth response—preserve the clinician-patient relationship—encompassed responsive behavior clinicians identified as important across the communication process, meaning it could intersect with each response goal (e.g., working to understand the misinformation is important to preserving the clinician-patient relationship).

While this initial study provided the foundation for developing a communication process model that reflect how clinicians respond to CTM, the findings were limited to one method—physicians' self-reports. Exploratory sequential research designs are optimal in model development to ensure initial products are validated and expanded upon with multiple or mixed methods, thereby validating findings as well as capturing a more comprehensive illustration of the phenomenon of interest. Observational research is vitally necessary to investigate whether this communication process is reflected in clinicians' observed behavior while they are in action—in other words, when they are actually communicating with patients during clinical encounters. Thus, we explored whether the clinicians' reported responses and associated strategies [20] were reflected using another method—by observing their behavior when responding to CTM in a clinical context. In doing so, we sought to both confirm and expand on the CTM communication process (i.e., the initial model) we previously developed [20].

2. Methods

2.1. Study design

Given the challenges of capturing CTM conversations in clinical settings [21], we used a qualitative observational design to develop a standardized role play with a trained actor, referred to as a standardized patient (SP). This approach has been effective in understanding multiple facets of clinician-patient communication including online searches [22], end-of-life communication, bad-news consultations, and patient-centered empathy skills [23]. To increase feasibility, we conducted role plays via Zoom, following procedures developed in a previous study [24].

2.2. Participants and recruitment

Participants were cancer clinicians (physicians, physician's assistants, or nurse practitioners). Hematology-oncology fellows and senior radiation oncology residents (PGY 3-5) were included. We contacted clinicians at our institutions and clinicians we knew from other institutions. We did not use the word "misinformation" with potential participants, instead introducing the study as a "research study to

understand how cancer clinicians, such as yourself, discuss cancer treatment misconceptions with patients." Participants were compensated with a \$50 e-gift card. The study was approved by the University of Florida IRB (#202301299).

2.3. Study procedures

We developed a clinical scenario (Fig. 1) for the clinicians and a patient script (Fig. 2) for the SP. A radiation oncologist (SBJ) and the senior author (CLB) wrote the patient script based on clinical and research experience. The script contained three questions about cancer treatment that were informed by common myths and misperceptions about cancer [25,26]. The SP (KD), a clinical educator with more than 10 years of experience, contributed to the refinement of the script by spending time online looking up the misinformation to develop the follow up questions and be able to more authentically talk about the CTM. We conducted three practice sessions with the SP to ensure that the technology worked well and that the timing was reasonable.

At least two days before their scheduled role play, clinicians were given the clinical scenario and a statement of participant rights. When they joined the Zoom call for the role play, the study coordinator confirmed they had reviewed the scenario and then answered questions. She began recording the interaction, and then invited the SP to turn on her camera. At that point the study coordinator turned off her camera and muted her microphone. The clinician began the role play by asking the SP how she was doing. The SP asked all three questions within each encounter and added in follow-up questions as previously developed on the script as needed with the goal of having a 10-min conversation with the clinician. If the role play had not naturally ended by the 10-min mark, the study coordinator stopped the role play. The study coordinator then excused the SP and asked the participant a few demographic questions, collected necessary information for the gift card, and shared a link to an anonymous 4-question survey, asking about their experience and comfort level with conversations with patients about cancer treatment misconceptions, as well as their comfort level with and their perception of the authenticity of the simulated interaction.

2.4. Data analysis

All audio recordings were professionally transcribed. Data were thematically analyzed using a constant comparative approach using both deductive and inductive analysis [27-30]. We deductively analyzed the data to confirm a priori themes, in other words, those responses and associated strategies previously identified in the clinician interview study that resulted in the initial communication process model [20]. We concurrently inductively analyzed the data to ensure we remained open to capture new responses/strategies not previously represented in the model or as clinicians initially self-reported [20]. Once the initial deductive and inductive analysis was conducted to confirm the pre-existing communication process model, we aimed to expand the model. A second round of deductive analysis was engaged to identify any strategies within each response previously identified (a priori themes), while concurrently inductively analyzing to be sensitive to new findings. Another level of analysis (axial coding) was enacted to further define each strategy by identifying skills clinicians enacted within each strategy to illustrate *how* they respond. Analyses were conducted by two co-authors with expertise in qualitative analyses (MDM, CLF), continuously refining the codebook. A third coder (TL) validated findings with a subset of the data to ensure rigor [31].

3. Results

Seventeen ($N = 17$) cancer clinicians participated. Five (29%) worked in radiation oncology, and 12 (71%) in medical oncology. About one-third ($n = 6$) were trainees, one was an advanced practice registered nurse, one was a nurse practitioner, while the remaining ($n = 9$) were

Patient Scenario
Clinical Communication about Cancer Treatment Misconceptions Study (PI: Bylund)

Veronica Miller is a 50-year old female patient who was diagnosed recently with a locally advanced breast cancer. She underwent a left mastectomy. Her oncology team, which includes you, in line with national treatment guidelines, is recommending adjuvant chemotherapy followed by radiation. Ms. Miller lives in a rural area in your cancer center's catchment area and has been making a 1-hour drive for appointments. She has an adult son who has accompanied her to visits before, but is not here today. Ms. Miller is meeting with you today as she is considering her treatment options and wants to discuss her options. Your task is to have a discussion with her like you would with a real patient.

You should start the role play by asking Ms. Miller, "How are you today?"

Fig. 1. Standardized patient scenario sent to participating clinicians.

In response to, "How are you today?"

Hi, doctor. I'm doing OK – thanks for asking. You know it's only been 4 weeks since I had my surgery. It's healing pretty well, though I'm still having a little pain. I was able to go out last weekend to my niece's soccer game which was the first time I've really been out in a while, so that felt good. Anyway, I've been doing a lot of reading about my cancer – it's just so hard to know where to go to get accurate information. I actually had a question I wanted to ask you if that's OK?

Patient Question 1: "I read online that exposing the cancer to air is bad. I'm concerned that I made the wrong decision by having surgery. Can cancer surgery or a biopsy cause cancer to spread in my body?"

Patient Question 2: "My cousin told me she listened to a podcast about chemo and radiation and how they poison people and burn them. It really made me think. What if I don't want to do those treatments?"

Patient Question 3: "My friend posted something on Facebook about how Vitamin C can cure cancer. I think I would like to try that, instead of chemotherapy or radiation. What do you think?"

Fig. 2. Standardized patient script.

practicing physicians (Table 1). Clinician-SP interactions lasted on average 9 min 28 s and resulted in 55 pages transcribed for analysis. Clinicians reported that over the past year, on average, they discussed CTM with about 13 patients per month ($M = 12.82$; $SD = 13.03$, $min = 1$ – $max = 50$). Participants reported high levels of comfort with these types of conversations in general. In addition, they perceived the SP encounter to be very authentic (Table 2).

Clinicians' communication with the SP reflected the same four overall responses identified in our first study [21], thereby validating the communication process clinicians engage in to address CTM. Clinicians 1) *work to understand the misinformation*, 2) *correct misinformation through education*, 3) *advise about future online searches*, and 4) *preserve the clinician-patient relationship*. In addition, the strategies clinicians initially reported using to enact each response were shown to be present in the current study also. These were also expanded upon given the observational study design, which yielded a more in-depth illustration of clinicians' strategies while also exemplifying the communication skills clinicians used within each strategy. This allowed us to extend the communication model by depicting not just what to do (e.g., responses and strategies) when responding to CTM, but *how* to do it (i.e., skills). Each of the four responses, their associated strategies, and respective skills are further explained below, offering a refined characterization of how cancer clinicians may respond to CTM (see Table 3). We depict these responses and strategies visually in the Misinformation Response Model, as shown in Fig. 3.

3.1. Response: work to understand the misinformation

Clinicians used strategies previously identified to understand the misinformation: 1) be open about own knowledge; 2) educate self/conduct search. Their behavior also reflected a third previously identified strategy (don't disparage/discount the information). This strategy was extended by illustrating how clinicians do not discount the information. Instead clinicians 3) take information seriously.

3.1.1. Be open about own knowledge

Clinicians were open about their knowledge limits using two skills. They *acknowledged their level of awareness of the information* by saying, "I'm not aware," "That's not what I know," or "I don't know." For instance, this clinician responded with openness about their knowledge when working to understand the information:

Do I think that vitamin C will be as good as these other treatments? Obviously, I don't know, and I definitely like to see the results of the science before I make a guess. But so far, I don't see enough data to think that it would be better. (Radiation Oncologist 1).

Clinicians also *hedged that it's hard to say for certain* what is correct, using statements like "I can't really comment on [issue]", "I'm not sure" and "I think vitamin C sometimes it's a little bit hard to say with certain, like alternative therapies" (Medical Oncologist 1).

Table 1
Participant demographics.

Participant demographics (n = 17)	n (%)
Sex	
Male	6 (35)
Female	11 (65)
Race	
White/Caucasian	10 (59)
Black/African American	3 (18)
Asian	4 (23)
Native Hawaiian/Pacific Islander	0 (0)
American Indian	0 (0)
Ethnicity	
Hispanic	0 (0)
Non-Hispanic	17 (100)
Degree Type	
MD	14 (88)
DO	1 (6)
NP	1 (6)
ARNP	1 (6)
PA	0 (0)
Clinician Type	
Trainee	6 (35)
Nurse Practitioner	1 (6)
Advanced Practice Registered Nurse	1 (6)
Physician	9 (53)
Years in Practice ^b	(n = 11)
1–5	1 (10)
6–10	3 (27)
11–15	5 (45)
16–20	0 (0)
21–25	2 (18)
Trainee PGY Level ^a	(n = 6)
Level 3	1 (17)
Level 4	0 (0)
Level 5	2 (33)
Level 6	2 (33)
Level 7	1 (17)
Specialty	
Radiation Oncology	5 (29)
Medical Oncology	12 (71)

Table 2
Participant survey responses.

	Mean (SD)	Min-Max
Comfort level while communicating with patients about cancer treatment misconceptions	4.24 (0.94)	1–5
Comfort level while communicating with the standardized patient about cancer treatment misconceptions	4.47 (0.61)	3–5
Perceived authenticity of the conversation with the standardized patient	4.65 (0.59)	3–5

3.1.2. Educate self/conduct search

Clinicians indicated they would educate themselves to understand the information by using two skills. They stated that they would learn more about the information. For example, this clinician responded, “If I don’t know the answer, then I will find out” (Radiation Oncologist 2). They also offered to look up the information. For instance, this clinician stated:

I can go ahead and look up the study, and we can kind of look at it together. And if you think that may be helpful, and I’m actually curious to look at it myself. (Radiation Oncologist 2).

3.1.3. Take information seriously

Clinicians responded by not disparaging or discounting the information and demonstrated that they took the information seriously by using four skills. Clinicians regularized the information content, acknowledging it was understandable that the patient asked about it. For example, this clinician stated, “That’s a common idea, so I

understand how you came across that and read that” (Radiation Oncologist 3). Clinicians also shared that other patients presented the same misinformation: “I’ve heard other people also mention that” (Medical Oncologist 4). Clinicians also confirmed which parts of the information were accurate by explaining that the information in its entirety was “not inaccurate” or “not false.” For example, a clinician responded to information that chemotherapy was poison: “The way that chemotherapy typically works is that it is in part a poison against the cancer. That is a not an inaccurate way of describing it” (Medical Oncologist 3).

Clinicians also contextualized the information to the patient’s distinct situation by clarifying that the information pertains to other contexts. For instance, in a response to misinformation about cancer needing, a clinician responded saying, “I think when you extrapolate that from other cancers, like certain types of testicular cancer, kidney cancer, there is the concern for when people go in with a biopsy it might actually spread the cancer elsewhere” (Medical Oncologist 1). Last, clinicians also took the information seriously in that they personalized the information to the patient him/herself. For example, this clinician addressed vitamin C information, recommending it as a supplement rather than a replacement to chemotherapy:

I think there’s a lot of really important things that you can do to help improve the health of your body ... vitamin C and other vitamins are very good examples of that. [explains high dosing of vitamin C needed in laboratory studies] ... But it’s not something that we would recommend as a replacement for the more tried and true and proven in your body treatments, such as the radiation or the chemotherapy. (Medical Oncologist 3).

Another clinician personalized information by identifying what the patient was interested in:

It sounds like you’re interested in natural alternatives to reduce your risk of breast cancer, and there is a lot of evidence that from high quality, large studies, ... that exercise, ... reduces recurrence. So, that’s something that you can add on to chemo and radiation and be part of a natural and holistic way to reduce your cancer recurrence risk. (Radiation Oncologist 3).

3.2. Response: correct misinformation through education

Clinicians used the strategies previously identified to correct misinformation through education: 1) state the information is incorrect; 2) explain why the information is incorrect; 3) emphasize the importance of a scientific base for quality information; and 4) refocus on the patient’s specific situation.

3.2.1. State the information is incorrect

Clinicians used two skills that varied in degree of assertiveness to correct information. Some clinicians used hedging statements less assertively, such as “I don’t agree.” For example, a clinician said, “I don’t really believe—I think it’s a myth when you say surgery can make cancer metastasize. I think it’s a myth” (Medical Oncologist 6). Clinicians also used explicit statements, like “It’s not correct” (Medical Oncologist 2). While no clinician specifically used the word “misinformation,” clinicians did classify information as “not correct” or “not accurate.”

3.2.2. Explain why the information is incorrect

Clinicians used four skills to explain why the information was incorrect. They explained how clinicians make recommendations or how their decisions are made, which included weighing benefits over risks, using a team of clinicians, and personalizing care. As this clinician explained, “We make these recommendations as a whole group of oncologists based on the fact that the benefit overall overshadows those potential risks” (Medical Oncologist 1). Clinicians also explained cancer and how it works in the body, addressing their specific type of cancer. As this clinician stated: “Breast cancer, in particular, what we tend to focus

Table 3
CTM responses, strategies, and skills.

CTM responses (themes)	CTM response strategies (subthemes)	CTM response enacted skills (properties)	Exemplar quotes	
1. Work to understand the misinformation	Be open about own knowledge	Acknowledge their level of awareness of the information	“Do I think that vitamin C will be as good as these other treatments? Obviously, I don’t know, and I definitely like to see the results of the science before I make a guess, but so far I don’t see enough data to think that it would be better.” (Radiation Oncologist 1)	
		Hedge that its hard to say for certain	“I think vitamin C, sometimes it’s, it’s a little bit hard to say with certain, like alternative therapies.” (Medical Oncologist 1)	
		State they will learn more about the information	“If I don’t know the answer, then I will find out.” (Radiation Oncologist 2)	
	Educate self/conduct search	Offer to look up the information	“I can go ahead and look up the study, and we can kind of look at it together. And if you think that may be helpful, and I’m actually curious to look at it myself, but again, as far as I know I haven’t seen anything showing that vitamin C can necessarily help people who have cancer specifically live longer, but again, we can look at that together.” (Radiation Oncologist 2)	
			Regularize the information content	“I’ve heard other people also mention that.” (Medical Oncologist 4)
		Confirm which parts of information are accurate	“The way that chemotherapy typically works is that it is in part a poison against the cancer. That is a not an inaccurate way of describing it.” (Medical Oncologist 3)	
		Contextualize the information	“I think when you extrapolate that from other cancers, like certain types of testicular cancer, kidney cancer, there is the concern for when people go in with a biopsy it might actually spread the cancer elsewhere.” (Medical Oncologist 1)	
	Take information seriously	Personalize the information	“There’s no harm in supplementing what we know otherwise to be good against the cancer with things like vitamin C and other vitamins that can help you be stronger.” (Medical Oncologist 3)	
			Use hedging statements	“So I don’t really believe—I think it’s a myth when you say surgery can make cancer metastasize. I think it’s a myth.” (Medical Oncologist 6)
			Use explicit statements	“It’s not correct.” (Medical Oncologist 2)
2. Correct misinformation through education	State the information is incorrect	Explain how clinicians make recommendations	“We make these recommendations as a whole group of oncologists based on the fact that the benefit overall overshadows those potential risks.” (Medical Oncologist 1)	
		Explain cancer and how it works in the body	“Breast cancer, in particular, what we tend to focus on is the hormones that the cancer is expressing because that’s what it uses to feed itself and to grow and so that’s what we usually focus on.” (Medical Oncologist 7)	
	Explain why the information is incorrect	Explain treatment-related processes	“Let’s say there’s an area in your body that’s your garden, like the breast cancer, where the breast is. When the breast cancer takes over, it’s like a weed in the garden, and I don’t know, have you ever weeded a garden and tried to take out the weeds? You know how sometimes you get some of the good leaves, the good vegetables that you’re trying to make, but it’s impossible to perfectly take out every single weed without getting a few plants. You still need to weed, right? Because otherwise, the weeds take over the garden, and even though you might get one leaf or one of your basil plants or some of the other plants, the garden comes back healthier once you’ve cleared the weeds. Does that make sense at all? That’s kind of what chemo and radiation are. Our goal is to only get rid of the weeds, the breast cancer.” (Medical Oncologist 11)	
			Counter the misinformation	“Actually, vitamin C can be a little bit also potentially harmful in a way if you’re receiving the radiation because it kind of counteracts the way that the radiation actually works. So, for people who are undergoing radiation, in particular, I typically tell them to stay away from high doses of vitamin C.” (Radiation Oncologist 4)
		Emphasize the importance of a scientific base for quality information	Situate correction within current state of scientific evidence	“This has all been borne out through a lot of research, a lot of work that’s been done. None of these treatments are being used kind of for the first time in your situation. These have all been tested, done, and the doses and the way in which this is done has been proven to be very reliable and very safe in thousands of patients that have come before you.” (Medical Oncologist 3)
			Address lab- versus human-based research	“We’ve had lots of things that work really well in dishes and lots of things that work really well in mice, and we’re so disappointed when they don’t work in people. So, it’s just that’s the due diligence we have to do to make it reach the level of evidence for us [that] is worth your time.” (Medical Oncologist 2)
	Refocus on patient’s specific situation	Explain the value of scientific evidence	“We have to keep our evidence levels all the same, meaning that like everything has to be put to the same test. So, these chemotherapy and radiation protocols, they’ve been compared against each other, and they’ve been compared against no treatment at all. And they’ve been shown to make people live longer and be cancer free for longer. No one’s done the same thing with vitamin C.” (Medical Oncologist 2)	
			Emphasize the individualization of cancer	“Different treatments affect different people in different ways. Some people will have more side effects and things like a skin burn or kind of like getting a really bad sunburn from where the radiation is [and] other people don’t. Some people will have side effects from chemotherapy where it makes them really sick and other people it won’t be so bad. And, unfortunately, it’s really hard for us to know in advance what you’re going to experience in terms of side effects from the treatment.” (Medical Oncologist 4)

(continued on next page)

Table 3 (continued)

CTM responses (themes)	CTM response strategies (subthemes)	CTM response enacted skills (properties)	Exemplar quotes
		Situate correction/education within patient’s cancer type	“I’ll just start by saying not in your case. So, it’s not something that you need to worry about. There in certain types of cancers, [explains cancer seeding]. But those are in very specific circumstances that don’t apply to the type of cancer that you have or the type of surgery that you had. So, this is not something that you need to worry about. That’s what it’s referring to, though.” (Medical Oncologist 8)
3. Advise about future online searches	Suggest sites or sources of information		“One really good resource for a lot of information on cancer education and why we make the decisions that we make is the National Conference of Cancer Network or nccn.org and it’s a great free resource for patients. So we don’t have to go looking all over the place on Google and I’m not sure what we’re looking at is verified or not.” (Medical Oncologist 2)
	Educate patient on type of scientific evidence to look for online		“But again, the kind of evidence you want to look for when you’re reading these things online is, was there a large number of women like me with a cancer like mine? And especially, if you see something where it looks interesting, and it was many years ago, you want to wonder why hasn’t that been tested in a large group of women, if it’s such a great idea. So, there’s more to the story.” (Radiation Oncologist 3)
4. Preserve the clinician-patient relationship	Cultivate openness	Validate the question about the information Emphasize the importance of discussing the information	“That’s a great question.” “I do appreciate the fact that you’re bringing these questions in, because that’s very important. What I find is when patients keep that to themselves and make decisions based on that, as providers, we really don’t get a chance to clarify any misconceptions that that might exist. So I appreciate the fact that you’re bringing it up.” (Medical Oncologist 7)
	Enact support	Validate that online information can be challenging/overwhelming	“These are very good questions and I am glad that there are so many different podcasts and things like that are out there, where people can share their experiences and get information out there. But the unfortunate thing is, it can also have some information out there that makes it confusing for people to make the right choices.” (Radiation Oncologist 2)
		Reassure the patient	“We are here to support you and get you through this” (Medical Oncologist 6)
	Empower the patient	Normalize the patient conducting their own searches Reaffirm the patient’s agency as the decision-maker	“First of all, wonderful that you’re reading and learning and educating yourself.” (Medical Oncologist 8) “I think the treatment of course is up to you. What we like is for you to have the best information so that you can make the best decision for yourself. But, of course, you have the ultimate say.” (Medical Oncologist 9)

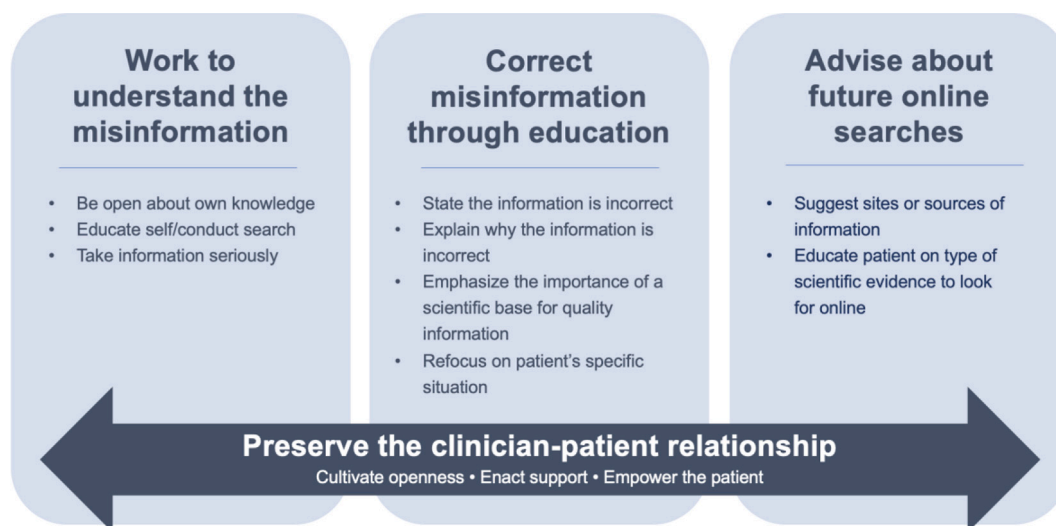


Fig. 3. Misinformation Response Model.

on is the hormones that the cancer is expressing because that’s what it uses to feed itself and to grow and so that’s what we usually focus on” (Medical Oncologist 7). Clinicians also *explained treatment-related processes* to correct and educate. This included explaining how chemotherapy and radiation work, side-effect management, and basic treatment steps:

It is kind of going into your body to deliberately kill the cancer and unfortunately there are some side effects from the chemotherapy that

can affect other parts of your body as well. So, it is a liquid, a liquid chemical, that is there to help destroy the cancer and radiation is a form of energy that penetrates through your body to also destroy the cancer. And it does so by essentially burning the cancer. (Medical Oncologist 3).

Some clinicians used metaphors to explain treatment:

Let’s say there’s an area in your body that’s your garden, like the breast cancer, where the breast is. When the breast cancer takes over,

it's like a weed in the garden, and I don't know, have you ever weeded a garden and tried to take out the weeds? You know how sometimes you get some of the good leaves, the good vegetables that you're trying to make, but it's impossible to perfectly take out every single weed without getting a few plants. You still need to weed, right? Because otherwise, the weeds take over the garden, and even though you might get one leaf or one of your basil plants or some of the other plants, the garden comes back healthier once you've cleared the weeds...Our goal is to only get rid of the weeds, the breast cancer. (Medical Oncologist 11).

Last, clinicians *countered the misinformation* by explaining that the opposite is true or how the information could be harmful. For instance, this clinician responded to a patient asking about replacing recommended treatment with vitamin C:

Actually, vitamin C can be a little bit also potentially harmful in a way if you're receiving the radiation because it kind of counteracts the way that the radiation actually works. So, for people who are undergoing radiation, in particular, I typically tell them to stay away from high doses of vitamin C. (Radiation Oncologist 4).

Another clinician stated in response to the SP asking about cancer seeding when exposed to air, "Quite the contrary. If you have the procedure, one would presume that you would be less likely to have disease spread, which is usually why it's the recommendation" (Medical Oncologist 10).

3.2.3. *Emphasize the importance of a scientific base for quality information*

Clinicians used three skills to emphasize the importance of scientific evidence. They *situated the correction within the current state of scientific evidence*, which at times included emphasizing the lack of scientific evidence present. For example:

This has all been borne out through a lot of research, a lot of work that's been done. None of these treatments are being used kind of for the first time in your situation. These have all been tested, done, and the doses and the way in which this is done has been proven to be very reliable and very safe in thousands of patients that have come before you. (Medical Oncologist 3).

Clinicians also *addressed lab- versus human-based research* to emphasize the importance of clinical trials and more sufficient evidence:

We've had lots of things that work really well in dishes and lots of things that work really well in mice, and we're so disappointed when they don't work in people. So, it's just that's the due diligence we have to do to make it reach the level of evidence for us [that] is worth your time. (Medical Oncologist 2).

Further, clinicians *explained the value of scientific evidence* to educate the patient on the type of data needed to support claims. For instance, this clinician explained how cancer treatments have been studied and tested:

We have to keep our evidence levels all the same, meaning that like everything has to be put to the same test. So, these chemotherapy and radiation protocols, they've been compared against each other, and they've been compared against no treatment at all. And they've been shown to make people live longer and be cancer free for longer. No one's done the same thing with vitamin C. (Medical Oncologist 2).

3.2.4. *Refocus on the patient's specific situation*

Clinicians used two skills to refocus the patient on their specific cancer experience. They *emphasized the individualization of cancer* by educating the patient on how everyone's cancer journey looks different:

Different treatments affect different people in different ways. Some people will have more side effects and things like a skin burn or kind of like getting a really bad sunburn from where the radiation is [and]

other people don't. Some people will have side effects from chemotherapy where it makes them really sick and other people it won't be so bad. (Medical Oncologist 4).

Clinicians also *situated the correction/education within the patient's cancer type*. For example, this clinician corrected the misinformation by explaining and reassuring the information on cancer seeding did not apply to this patient's situation:

I'll just start by saying not in your case. So, it's not something that you need to worry about. ... [explains cancer seeding]. But those are in very specific circumstances that don't apply to the type of cancer that you have or the type of surgery that you had. So, this is not something that you need to worry about. (Medical Oncologist 8).

3.3. *Response: advise about future online searches*

Clinicians used all but one of the strategies previously identified to advise about future online searches: 1) suggest or recommend sites or sources; and 2) educate patient on type of scientific evidence to look for online.

3.3.1. *Suggest sites or sources of information*

Clinicians directed patients to credible sites for future searches. These included the National Conference of Cancer Network (NCCN), the National Cancer Institute (NCI), and the American Cancer Society (ACS). For instance, this clinician redirected the patient to a credible source:

One really good resource for a lot of information on cancer education and why we make the decisions that we make is the National Conference of Cancer Network or nccn.org. And it's a great free resource for patients. So, we don't have to go looking all over the place on Google, and I'm not sure what we're looking at is verified or not. (Medical Oncologist 2).

3.3.2. *Educate patient on type of scientific evidence to look for online*

Clinicians also used an education-based strategy and explained what to look for online to ensure the information was scientific or accurate. For example, this clinician emphasized critical inspection of online information, using science-led questions:

But again, the kind of evidence you want to look for when you're reading these things online is, was there a large number of women like me with a cancer like mine? And especially, if you see something where it looks interesting, and it was many years ago, you want to wonder why hasn't that been tested in a large group of women, if it's such a great idea. (Radiation Oncologist 3).

3.4. *Response: preserve the clinician-patient relationship*

Clinicians preserved their relationship with the patient using previously identified strategies while providing more clarification of the process. One previously identified strategy (be open-minded and supportive) was separated to fully capture the communicative process: 1) cultivate openness; 2) enact support. In addition, clinicians did not disparage, criticize nor discount the patient (a previously identified strategy); however, this strategy was expanded to illustrate what clinicians do instead: 3) empower the patient. While clinicians also praised the patient's efforts (a previously identified strategy), their behavior reflected two contexts in which they do this aligned with specific skills (cultivate openness and empower patients), further explained below.

3.4.1. *Cultivate openness*

Clinicians used two skills to cultivate openness with the patient. First, they praised patient's efforts in that they *validated the question about the information*, saying "That's a great question" and "good point."

Clinicians also *emphasized the importance of discussing the information*. For example:

I do appreciate the fact that you're bringing these questions in because that's very important. What I find is when patients keep that to themselves and make decisions based on that, as providers, we really don't get a chance to clarify any misconceptions that might exist. (Medical Oncologist 7).

3.4.2. Enact support

Clinicians facilitated support through two skills. They *validated that online information can be challenging/overwhelming*, highlighting how much information exists and the difficulty of sifting through it all:

I am glad that there are so many different podcasts and things like that are out there where people can share their experiences and get information out there. But the unfortunate thing is, it can also have some information out there that makes it confusing for people to make the right choices. (Radiation Oncologist 2).

Clinicians also *reassured the patient*: “We are here to support you and get you through this” (Medical Oncologist 6).

3.4.3. Empower the patient

Clinicians were careful not to criticize or disparage the patient by instead empowering her using two skills. First, they *normalized the patient conducting their own searches*, which involved praising their efforts. This entailed framing the patient's actions as positive and encouraging her to continue her efforts to inform themselves: “First of all, wonderful that you're reading and learning and educating yourself” (Medical Oncologist 8). Clinicians also *reaffirmed the patient's agency as the decision maker*, validating decisions already made and emphasizing their control: “You made a great decision to do the surgery. I hope you have peace about that, because the only way that we can cure or get rid of breast cancer permanently will involve surgery like you had” (Radiation Oncologist 3). In another example, a clinician emphasized the patient's agency in deciding future steps in conjunction with the clinician's role: “I think the treatment of course is up to you. What we like is for you to have the best information so that you can make the best decision for yourself. But, of course, you have the ultimate say” (Medical Oncologist 9).

4. Discussion and conclusion

4.1. Discussion

This study builds on our previous work, collectively providing a foundation for developing a model of misinformation responses. We verified that the four responses clinicians self-reported using in our interview study [20] are the same responses enacted in action or simulated practice. Furthermore, because of the observational design, we were able to expand on these strategies, identifying specific skills clinicians can use to respond to CTM. Most notably, this allowed for the typology originally created to expand from not just what clinicians do to respond to misinformation (e.g., correct the misinformation) and the strategy to use (e.g., explain why the information is incorrect) but by showing *how* they do it—the skills (e.g., explaining treatment-related processes). Only one strategy that clinicians previously identified in the interview study—ask about the source of the information—was not reflected in clinicians' observed behavior. The SP in this study presented the misinformation by naming a source (e.g., friend posted online, cousin heard from a podcast), which may have influenced the lack of questions from the clinicians about the source.

Many of the strategies and skills that emerged in this data coincide with recommended communication practices for oncology settings [4,28,32]. Overall, the clinicians in this study exemplified patient-centered communication by educating patients while being

approachable and encouraging. Our resulting Misinformation Response Model (see Fig. 3) includes both conceptual applications (i.e., clinicians' responses and associated strategies to misinformation) and concrete applications (i.e., skills clinicians can enact in response to misinformation). Given the observational approach, we also now have tangible, narrative-focused tools clinicians can use to model their responses to patients about misinformation.

A strength of the Misinformation Response Model is its flexibility to be used with different types of (mis)information. Information is not always binary (true or false) and may instead fall upon a spectrum. In fact, in a recent study [2], we asked experts to rate information on a 5-point scale, with “true information” and “false information” being the anchors. The Misinformation Response Model can work both for patient statements that are along that spectrum.

4.1.1. Teaching clinicians CTM responses, strategies, and skills

Our findings indicate that as clinicians discuss misinformation with patients, they can respond sequentially by first working to understand the misinformation before correcting the patient through education and advising about future online searches. These first three responses to CTM are information-oriented goals that clinicians can strive for using our specified strategies and skills. Within these information-oriented response goals, clinicians can concurrently work to preserve the clinician-patient relationship, an interpersonal-oriented goal (see Fig. 3). It is important to note that the interpersonal-oriented goals are intertwined with the information-oriented goals and that within the clinician-patient interaction, enacted strategies and skills based on these goals will overlap and cannot be separated. The Misinformation Response Model also outlines the specific strategies and skills that can be enacted to obtain these goals.

4.1.2. Exemplar

For example, in response to a patient asking about replacing recommended chemotherapy with vitamin C due to an article they read online, a clinician may first work to preserve the relationship by validating the question, while simultaneously working to understand the information by taking the information seriously and normalizing it: “That's a great question. I've heard other people also mention that concern as well.” Next, the clinician may correct the misinformation through education and state something like the following:

It turns out that there actually has been some research that shows it could inhibit your treatment, especially when it's given with chemotherapy or radiation. The radiation and the chemotherapy, they're causing damage to the tissue. That's what they're supposed to do—to cause damage as the main focus is to treat any residual cancer that might still be there. But then vitamin C actually is an antioxidant, so it reverses or it kind of heals things up. So, then if you're trying to kill the cancer cells, but you're going against it with the vitamin C, then that could actually be bad if you're trying to kill the cancer cells.

This explanation combines several correction skills, including 1) counter the misinformation (e.g., explaining how vitamin C can be harmful), 2) explain treatment-related processes (e.g., what radiation and chemotherapy do in the body), and 3) situate correction within the current state of scientific evidence (e.g., explain that research shows vitamin C can be harmful). A clinician may then advise the patient about future online searches directing them to online credible sources or by educating them on what to look for when online. Finally, a clinician may close their response by further preserving the relationship through empowering the patient and/or enacting support. For example, “[It's] wonderful that you're reading and learning and educating yourself, and, of course, you have the ultimate say. We are here to support you and get you through this.” Collectively, this exemplar shows the progression of the Misinformation Response Model and how clinicians can move through each phase to thoroughly respond to the patient's

misinformation while preserving empathy, respect, and trust.

4.1.3. Limitations and future research

The Misinformation Response Model has some limitations. Our choice of method means it may not fully represent conversations with real patients. However, clinicians in the study rated their experience talking to the SP as very authentic, and previous research shows that visits with SPs are predictive of visits with actual patients [22,23]. Additionally, the model is descriptive, rather than prescriptive. Future research can help us understand how these responses, strategies, and skills relate to patient outcomes, which could lead to evidence-based practice guidelines for clinicians on responding to cancer treatment misinformation.

Clinicians were not completely blinded to the purpose of the study. We believe it would have been difficult to recruit busy clinicians to a generic standardized patient discussion. Additional limitations include a sample of mostly white, non-Hispanic, female participants that were recruited primarily from one institution. Future studies should work to diversify sampling. There may also have been self-selection bias as participants may have been clinicians that already feel confident in misinformation responses or that value quality health care communication. Our analysis also focuses on clinicians' responses and does not include how the patient responded or felt about the clinician's response to their questions. Thus, further research is needed to garner the full picture of CTM response best practices. We also recommend the model be evaluated with a randomized controlled trial—a next step in the exploratory sequential design framework for model development. Further, there may be more opportunity for further research at the linguistic level, analyzing clinician-patient communication in more detail.

4.2. Innovation

This is the first published research study observing clinician communication about CTM. The study's novel methods and findings fill an important gap and enhance our understanding of CTM responses. As the first study to use SP encounters to examine CTM responses, we were able to identify skills that clinicians use in practice to fully develop a Misinformation Response Model for CTM. This model highlights 1) how clinicians respond to cancer misinformation, 2) what strategies are employed within each type of response, and 3) the skills used to enact each strategy while interacting with a patient. This model can be used to educate and train oncology clinicians, supplying conceptual understanding as well as concrete communication skills to apply in oncology practice settings.

4.3. Conclusion

In conclusion, this study establishes the Misinformation Response Model by providing oncology clinicians with a roadmap for responding to misinformation with associated strategies and skills to utilize. This model can lead to training to enhance clinicians' ability to respond to cancer treatment misinformation. Future research can expand on which clinician CTM responses, strategies, and skills are most critical to enhancing patient health outcomes.

CRedit authorship contribution statement

M. Devyn Mullis: Writing – review & editing, Writing – original draft, Formal analysis. **Carla L. Fisher:** Writing – review & editing, Writing – original draft, Formal analysis, Conceptualization. **Skyler B. Johnson:** Writing – review & editing, Methodology, Conceptualization. **Tianshi Liu:** Writing – review & editing, Investigation, Formal analysis. **Tithi B. Amin:** Writing – review & editing, Project administration, Investigation, Conceptualization. **Sherise Rogers:** Writing – review & editing, Investigation. **Kennan DeGruccio:** Writing – review & editing, Investigation, Conceptualization. **Carma L. Bylund:** Writing – review &

editing, Writing – original draft, Supervision, Investigation, Formal analysis, Conceptualization.

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.

References

- [1] Hutten RJ, Weil CR, Barney BM, et al. Complementary and alternative medicine exposure in oncology (CAMEO) study: a multi-institutional cross-sectional analysis of patients receiving cancer treatment. *J Clin Oncol* 2022;40(16_suppl):e18739. https://doi.org/10.1200/JCO.2022.40.16_suppl.e18739.
- [2] Johnson SB, Parsons M, Dorff T, et al. Cancer misinformation and harmful information on Facebook and other social media: a brief report. *J Natl Cancer Inst* Jul 11 2022;114(7):1036–9. <https://doi.org/10.1093/jnci/djab141>.
- [3] Johnson SB, Bylund CL. Identifying cancer treatment misinformation and strategies to mitigate its impacts with improved radiation oncologist-patient communication. *Pract Radiat Oncol* 2023;13(4):282–5. <https://doi.org/10.1016/j.prro.2023.01.007>. Epub 2023 Feb 2. PMID: 36736620.
- [4] Street Jr RL, Makoul G, Arora NK, Epstein RM. How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Educ Couns* 2009;74(3):295–301.
- [5] Pan W, Liu D, Fang J. An examination of factors contributing to the acceptance of online health misinformation. *Front Psychol* 2021;12:630268.
- [6] Laato S, Islam AN, Islam MN, Whelan E. What drives unverified information sharing and cyberchondria during the COVID-19 pandemic? *Eur J Inf Syst* 2020;29(3):288–305.
- [7] Jimenez T, Restar A, Helm PJ, Cross RI, Barath D, Arndt J. Fatalism in the context of COVID-19: perceiving coronavirus as a death sentence predicts reluctance to perform recommended preventive behaviors. *SSM Popul Health* 2020;11:100615.
- [8] Epstein RM, Street Jr RL. Patient-centered communication in cancer care: promoting healing and reducing suffering. 2007.
- [9] Johnson SB, Park HS, Gross CP, Yu JB. Use of alternative medicine for cancer and its impact on survival. *J Natl Cancer Inst* 2018;110(1):121–4.
- [10] Johnson SB, Park HS, Gross CP, James BY. Complementary medicine, refusal of conventional cancer therapy, and survival among patients with curable cancers. *JAMA Oncol* 2018;4(10):1375–81.
- [11] Ryan H, Schofield P, Cockburn J, et al. How to recognize and manage psychological distress in cancer patients. *Eur J Cancer Care* 2005;14(1):7–15.
- [12] Arora NK. Interacting with cancer patients: the significance of physicians' communication behavior. *Soc Sci Med* 2003;57(5):791–806.
- [13] Yıldırım S, Kazaz SN, Semiz HS, et al. An evaluation of the information sources of cancer patients' relatives. A prospective survey. *J Cancer Educ Oct* 2019;34(5):913–9. <https://doi.org/10.1007/s13187-018-1395-8>.
- [14] López-Gómez M, Ortega C, Suárez I, et al. Internet use by cancer patients: should oncologists 'prescribe' accurate web sites in combination with chemotherapy? A survey in a Spanish cohort. *Ann Oncol Jun* 2012;23(6):1579–85. <https://doi.org/10.1093/annonc/mdr532>.
- [15] Williams JS, Fong-Gurzinsky J, Nagavally S, et al. Preferences in trust regarding the provision of cancer information among adults. *J Natl Med Assoc Aug* 2021;113(4):457–64. <https://doi.org/10.1016/j.jnma.2021.03.003>.
- [16] Camacho-Rivera M, Gonzalez CJ, Morency JA, Blake KD, Calixte R. Heterogeneity in trust of cancer information among hispanic adults in the United States: an analysis of the health information National Trends Survey. *Cancer Epidemiol Biomarkers Prev Jul* 2020;29(7):1348–56. <https://doi.org/10.1158/1055-9965.Epi-19-1375>.
- [17] Jackson DN, Peterson EB, Blake KD, Coa K, Chou WS. Americans' trust in health information sources: trends and sociodemographic predictors. *Am J Health Promot Nov* 2019;33(8):1187–93. <https://doi.org/10.1177/0890117119861280>.
- [18] Hesse BW, Nelson DE, Kreps GL, et al. Trust and sources of health information: the impact of the internet and its implications for health care providers: findings from the first health information National Trends Survey. *Arch Intern Med* 2005;165(22):2618–24. <https://doi.org/10.1001/archinte.165.22.2618>.
- [19] Peterson JS, Swire-Thompson B, Johnson SB. What is the alternative? Responding strategically to cancer misinformation. *Future Oncol Sep* 2020;16(25):1883–8. <https://doi.org/10.2217/fon-2020-0440>.
- [20] Bylund CL, Mullis MD, Alpert J, Markham MJ, Omega T, Fisher CL, Johnson SB. Clinician Communication With Patients About Cancer Misinformation: A Qualitative Study. *JCO Oncol Pract* 2023;19(3):e389–96. <https://doi.org/10.1200/OP.22.00526>. Epub 2023 Jan 10. PMID: 36626708.
- [21] Bylund CL, D'Agostino TA, Ostroff J, Heerd A, Li Y, Dickler M. Exposure to and intention to discuss cancer-related internet information among patients with breast cancer. *J Oncol Pract Jan* 2012;8(1):40–5. <https://doi.org/10.1200/jop.2011.000271>.
- [22] Bylund CL, Sperka M, D'Agostino TA. Formative assessment of oncology trainees' communication with cancer patients about internet information. *Palliat Support Care Apr* 2015;13(2):197–200. <https://doi.org/10.1017/s1478951513000928>.
- [23] Siminoff LA, Rogers HL, Waller AC, et al. The advantages and challenges of unannounced standardized patient methodology to assess healthcare

- communication. *Patient Educ Couns* 2011;82(3):318–24. <https://doi.org/10.1016/j.pec.2011.01.021>. 2011/03/01.
- [24] Bylund CL, Thompson LA, Hansen M, Staras SAS. A pilot test of a workshop for pediatric clinicians about communicating with parents about the HPV vaccine using the C-LEAR approach. *J Cancer Educ Jun* 2023;38(3):798–804. <https://doi.org/10.1007/s13187-022-02188-2>.
- [25] Johnson SB, King AJ, Warner EL, Aneja S, Kann BH, Bylund CL. Using ChatGPT to evaluate cancer myths and misconceptions: artificial intelligence and cancer information. *JNCI Cancer Spectr Mar 1* 2023;7(2). <https://doi.org/10.1093/jncics/pkad015>.
- [26] National Cancer Institute at the National Institutes of Health. Common Cancer Myths and Misconceptions. Updated Nov 9, 2023, <https://www.cancer.gov/ab-out-cancer/causes-prevention/risk/myths>; Dec. 21, 2023.
- [27] Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. *Int J Qual Methods* 2006;5(1):80–92. <https://doi.org/10.1177/160940690600500107>.
- [28] Roberts K, Dowell A, Nie J-B. Attempting rigour and replicability in thematic analysis of qualitative research data; a case study of codebook development. *BMC Med Res Methodol* 2019;19(1):66. <https://doi.org/10.1186/s12874-019-0707-y>. 2019/03/28.
- [29] Glaser BJ, Strauss AL. *The discovery of grounded theory: strategies for qualitative research*. Adline Publishing Company; 1967.
- [30] Strauss A, Corbin J. *Basics of qualitative research: techniques and procedures for developing grounded theory*. Sage; 1998.
- [31] Morse JM, Barrett M, Mayan M, Olsen K, Spiers J. Verification strategies for establishing reliability and validity in qualitative research. *Int J Qual Methods* 2002;1:1–19.
- [32] Brown RF, Bylund CL. Communication skills training: describing a new conceptual model. *Acad Med Jan* 2008;83(1):37–44. <https://doi.org/10.1097/ACM.0b013e31815c631e>.