How oncologists communicate information to women with recurrent ovarian cancer in the context of treatment decision making in the medical encounter

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Abstract

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Background Women with recurrent ovarian cancer depend on their physicians to provide them with information about their diagnosis and available treatment options if they wish to participate in the process of choosing the treatment. There is no information on how oncologists give information to women during the physician–patient encounter at the time the disease recurs.

Objectives To explore from the oncologists' perspective (i) the extent to which oncologists provide their own patients who are experiencing their first recurrence of ovarian cancer with the same information about management options, and (ii) any explicit or implicit criteria they use to decide whether and how to tailor the information to individual patients.

Methods We adopted a qualitative, exploratory descriptive approach to begin to understand oncologists' perspectives on how they gave information to patients within the context of their clinical practice. Individual interviews were used to identify themes related to the study objectives.

Results Fifteen gynaecologic and five medical oncologists participated. Theme 1 describes the extent to which oncologists give information to their patients in the same way or in different ways. This section describes how the same oncologist may modify the depth of information transfer based on several factors. Theme 2 focuses on the factors that influence what information is given. For example, the amount and type of information given is based on the oncologist's on-going assessment of how the patient is assimilating the information shared during the medical encounter, the oncologists' perception of their relationship with the patient and the oncologist's assessment of what role they should take in decision making.

Theme 3 involves the factors that influenced how information is given. For example, the information shared may vary based on the oncologist's perception of the patient's vitality, the patient's comprehension of the information, the patient's emotional well-being. In addition, the oncologist may make the information relevant for the patient by using analogies. Different types of information may be shared based on the oncologist's perception of patient- or family-initiated question. The information relay may be curtailed based on competing demands for the oncologist.

Discussion and Conclusions Oncologists provide women with information on their disease status, their treatment options and the side effects of treatment. The oncologists use perceptions to determine what information and how to provide information. The question this paper raises is whether the oncologist's perceptions reflect the individual patient's information and decision-making needs.

Introduction

Ovarian cancer is usually characterized by a waxing and waning course of symptoms. When the disease is advanced, there are symptoms such as abdominal bloating. When the disease responds to treatment, the symptoms resolve and quality of life improves for a time. Unfortunately, the cancer invariably re-grows and the cycle of symptoms–treatment–response–recurrence–symptoms continues. During their journey with this disease, women with ovarian cancer have several types of encounters with the medical system. Some of these encounters involve making a treatment decision. There is little information about what transpires during a treatment decision-making encounter in the circumstance of chronic disease, which ultimately results in death. One aspect of treatment decision making involves the relay of information from the oncologist to the patient. There is a small amount of literature addressing what type of information oncologists' feel women with recurrent ovarian cancer should review.^{1,2} In a previous published paper, we explored from the ovarian cancer oncologist's perspective what transpired during the medical encounter. We showed that most oncologists come to the encounter with specific information that they feel needs to be imparted about the status of the patient's ovarian cancer and

her current treatment options. These oncologists felt it was important to provide treatment choices to their patients as this gave hope to patients in the event the chosen treatment was unsuccessful. The oncologists reported being quite vague about providing patients with survival information and only addressed survival information when the patient or family asked specific questions.¹ Donovan *et al.*,² in creating a decision board for determining treatment preferences of women with recurrent ovarian cancer, identified from medical colleagues the types of information they felt women required in order to make a treatment choice, that is, information about ovarian cancer, information about management options, information about benefits and side effects of each management option and so on. However, there are no studies in the literature on the oncologists' perspective of the process of information giving for women experiencing their first recurrent of ovarian cancer. In other words, do oncologists give the same information to their patients? What are the factors that influence the information that is provided to these women and how it is provided? Thus, we undertook this qualitative study to explore and describe what occurs during the encounter between an oncologist and woman with ovarian cancer at the point in her journey when the ovarian cancer first recurs.

In this paper, we further explore the oncologists' perspective on information giving to women at the time of their first recurrence with ovarian cancer. We were interested in understanding whether oncologists have a standard set of information that they present in the same way to all of their patients or whether they have a more general idea of topics they want to cover but vary the content and way of presenting this information, depending on the individual patient that they are talking to. The specific objectives were to understand (i) the extent to which oncologists provide their own patients who are experiencing their first recurrence of ovarian cancer with the same information about management options and (ii) any explicit or implicit criteria that oncologist use to decide whether and how to tailor the information to individual patients.

Methods

Design

We adopted a qualitative, exploratory descriptive approach to begin to understand physicians' perspectives, experiences and constructions of meaning that influenced how they gave information to patients within the context of their clinical practice.³ This approach is appropriate when exploring new areas of research where little information is available. This approach also enabled us to learn directly from oncologists in their own words about those factors that influence how they communicate information about treatment to recurrent ovarian cancer and treatment to their patients. We used an emergent and inductive approach to data collection and analysis, in order to derive important themes about information giving from the responses of the physicians themselves rather than from the researchers' preconceived world views or theories.⁴

Selection and recruitment of oncologists

In Ontario, Canada, both gynaecologic and medical oncologists provide chemotherapy as

first-line treatment when ovarian cancer is diagnosed and at disease recurrence. We sent an email invitation asking all gynaecologic and medical oncologists in Ontario cancer centres and outreach hospital clinics to participate in our study. To be eligible for inclusion in the study at least one-third of the oncologists' practice had to involve women with ovarian cancer, including the provision of chemotherapy to women with recurrent ovarian cancer. The study research coordinator checked the eligibility of the oncologists who were willing to participate. An interview appointment with the research coordinator was arranged at a mutually convenient time.

Development and pilot testing of the interview guide

A semi-structured interview guide was developed to explore oncologists' perspectives about what information and how they communicate information to patients at the time of the patient's first recurrence of ovarian cancer, the treatment options and potential outcomes in the medical encounter. The topics addressed in the interview guide were based on the study objectives (Table 1). More specific questions and initial probes were developed for each topic area.

The interview guide went through several iterations before being pilot-tested. The guide was pilot-tested with two community medical oncologists who treat women with recurrent ovarian cancer. Minor changes were subsequently made to improve the interview flow.

Data collection

In most cases, the interviews took place in person in the physician's private office, but due to geographic limitations, a few interviews took place by telephone. The interview was conducted by the research coordinator (JR) who has extensive experience in qualitative research and interviewing. Interviews were tape-recorded and transcribed. Each transcript was compared for accuracy with the original audio-taped

Table 1 Interview guide

Item	Questions and probes
1	To document from the physicians' perspective the key issues that are reviewed when a woman presents with ROC How do you break the news of recurrent disease? Do you discuss what this means? Do you discuss what it means that the disease has come back?
2	To understand from the physician's perspective the extent to which physicians have different ways/methods of giving information to patients and to classify these methods (how and what) Scenario – In a patient who presents with disease recurrence 3 months after finishing first line chemotherapy..... Tell me what you would say to the patient Do you think there are treatment options for this patient? What are they? Do you give the patient treatment options or just a treatment recommendation? Can you explain what influences your decision? What information do you give concerning the options? How do you describe outcome information? How do you provide the information to patients?
3	To explore the extent to which the same physician presents information differently to different patients When you meet with the patient, what in the encounters triggers you to present the information differently from one patient to the next? Are you in the habit of determining what role the patient wants in the decision making process? If yes – how do you do this? If no – why not? How do you handle the delivery of information when a patient is from a different culture? Does the information exchange differ if this patient is a new consult vs. a patient who you have treated in the past? If so, how does the exchange differ? How do you handle the dynamic of family or friends present during the encounter?
4	To identify any explicit or implicit criteria that physicians use to make these choices [i.e. do physicians identify cues (either from the patient or the context) that influence what and how they give information to patients relevant to TDM (for example, the domains of information covered, i.e. prognosis, goals of treatment, side effects, process of receiving treatment, follow-up, level of details, number of visits over which the information is exchanged or the TDM takes place] Are there cues (verbal and non-verbal) that occur during the interaction that cause you to tailor the information about: Outcome Options Treatment? Do you routinely push for a treatment decisions for managing ovarian cancer recurrence made at a single visit? If so, why. If not, why not?

interview. The interviewer kept an audit trail, completing a structured abstract of each interview transcript, making notes on new concepts generated from each interview and recording the contribution of each interview to the overall study objectives and interview process. On average, the interview lasted 1 h.

Data analysis

In exploring the data, we first reviewed the transcripts to identify relevant data segments related to the overall research questions. The

initial list of codes was developed inductively by coding an initial sample of interview transcripts. These codes were then discussed with the entire multidisciplinary research team at regular team meetings. Then, a sample of six interviews were selected for independent coding by two team members (STG, IG) in order to explore inter-rater reliability in coding. Results were compared and any discrepancies discussed and resolved. Guidelines (decision rules) for coding were developed in order to promote intra- and inter-rater consistency in coding subsequent study transcripts. The two coders met

after coding sequential groups of five interviews until 80% inter-rater reliability was achieved on the higher-order more general codes. Additional interview transcripts were then coded and discussed with team members to identify any overlap in categories. Codes were further refined and a comparative method was used to compare data with emergent codes, the relationship among codes and the development of themes from initial codes.^{5–7} The themes were related to the objectives of the study. All transcripts, codes and themes comprise a database in NVivo®, a qualitative research analysis software program for storing, managing, coding and analysing qualitative data.^{8,9}

Ethics

This study received approval by the McMaster University Research Ethics Board, Hamilton, Canada. Written consent was obtained from study participants prior to the interviews. There were no individual identifiers included in the study tapes, questionnaires or transcripts. All study materials were stored in a locked file cabinet at the study cancer centre. All participants reviewed and signed an informed consent prior to participation.

Results

Response rates

The response rate was 65% (15/23) of the invited gynaecologic oncologists and 33% (5/15) of the medical oncologists participated. There are six cancer centres in Ontario that have gynaecologic oncologists, but only 5 of these six centres have a medical oncologist who treats women with ovarian cancer. Looking only at those centres where gynaecologic oncologists practise, there were no gynaecologic oncologists who responded from one centre (of 6) and no medical oncologists who responded from two (of these 6). We had invited medical oncologists to participate from 6 other smaller cancer centres that do not have a gynaecologic

oncologist. None of the medical oncologists from these centres were willing to participate. To be eligible to participate in this study, one-third of the oncologists' practice had to involve women with ovarian cancer. It was not clear how many of those who did not participate self-selected as being not eligible.

Demographics of respondents

All twenty respondents were interviewed to explore their perceptions of factors influencing their communication of information related to treatment decision making to women with recurrent ovarian cancer. In general, these physicians were either in their early years of practice (44.5% < 5 years in oncology practice) or very experienced (44.5% 21–25 years in oncology practice). Slightly less than half of the physicians (44.4%) were aged 51–65 years, and most of these physicians had been trained in Ontario, Canada. The majority of participants were gynaecologic oncologists (78%) and were male (78%). As a comparator, in Ontario, among the non-responders from centres with a gynaecologic oncologist, 67% were gynaecologic oncologists and 58% were male.

Themes

Three broad themes emerged from the data. The first theme involved the oncologists' 'information-giving style'. In other words, the extent to which an oncologist gives information in the same way to all of their patients (Objective 1). We found that a few oncologists give the same information to every patient. Most described contexts where they tailor the information about treatment, side effects and outcomes. The second theme focused on the factors that influenced *what* information is given in terms of the topic areas (i.e. disease status, treatment options) and level of detail. In other words, those implicit or explicit factors that the oncologist reported led them to tailor the information they gave to patients. The third theme focused on cues that influenced *how* the information is given. Here, oncologists described

cues that occurred during the medical encounter that influenced how they provided the information. Typically, these cues were related to the patient. These cues had an immediate effect of re-shaping the oncologist's behaviour. Themes 2 and 3 are different aspects of Objective 2. We elected to present theme 3 separately from theme 2 because theme 3 highlights the immediacy of how these cues influenced the oncologist's information giving and the decision-making process.

Theme 1: information-giving style: the extent to which an oncologist gives the same information to all of their patients or varies this information from patient to patient (Objective 1)

The way an oncologist provides information to the patient includes the domains covered in the interaction (i.e. status of the disease, treatment options, treatment details, side effects) and the amount of information provided in each of these domains. There were two broad information-giving styles reported by the oncologists. On the one hand, a few oncologists reported giving exactly the same information in a very factual manner (i.e. domains and depth) to every patient independent of the patient's demographic or psychological make-up.

I usually try and give everybody the same message that it is incurable and what we're doing is basically chemotherapy with the idea of reducing tumor volume and reducing complications but not really cure. (Participant 11)

So, my strategy is fairly straight-forward. I present the facts. I present the data that we have in front of us. I present the treatment options that are available based on the data that we have in front of us. I try to go over the pros and cons of each of those treatments and I support them in the decisions they make and be there for questions or clarifications that they have with regards to those decisions. (Participant 13)

Another style involved using analogies to describe specific domains of information.

I use a weed analogy. I use a mould analogy. I use a crystal ball analogy. I use a rust analogy. I

use, those are my main ones those four. That the ovarian cancer can be like a dandelion infestation. So there is what you can see and what you can't. And then we stumble across the problem - a yard has dandelions sort of dispersed all over the place and in certain areas there are clumps and in other areas there are singular dandelion growths and other areas there has got to be seed and shoots that you can't even see. And there are, if you want to get a bit creative, in the backyard certain garden beds or trees if you can't sacrifice that the dandelions are all growing within. So the treatment for the problem or the management is to mostly spray the dandelions because you can never pluck them all out of the ground. But the problem is that the weed killer that you use is a bit toxic to the grass. You've got to be careful how you use it and also the weed killer you use can't kill all the dandelions. And to the contrary, the more that you use eventually the dandelions become resistant to the weed killer. So the problem becomes an ongoing management dilemma. How do you control the dandelions? And the definition of or the goal is not to kill the lawn, well that is the goal but that can't be accomplished. So the realistic deliverable is to. (Participant 10)

While most of the oncologists reported covering the same domains of information, these oncologists clearly described modifying the depth of information based on several factors. These can be related to the patient, the physical environment (private room in a clinic vs. bedside in a four bed hospital room), presence of other relatives or friends to name a few.

I think a lot of it is really...how receptive they are, going to be and if they're really falling to pieces I'm just going to give them very broad information rather than kind of getting into specific details because they're just not going to, I think I'm just going to make a bad situation worse. And often it's just a matter of having a discussion about you know what this means and immediately take care of some of their anxiety and symptom control issues and then giving them a package of information that they can take home...They're better off kind of going home having a chance to get back their senses and go over the information you gave them and go over and write some questions down and come back in and have a more detailed discussion afterwards. (Participant 7)

We have shown that information-giving style includes the way the information is given to patients (factually vs. using analogies); the domains of information provided are fairly consistent across providers; however, most oncologists indicate that the depth of information provided within each domain does vary between patients. Theme 1 and 2 do overlap in this area of depth of information.

Theme 2: the factors that influence *what information* is given

The factors that influence *what information* the oncologist gives as derived inductively from our study are grouped into the following sub-themes: (i) the oncologist's on-going assessment of how the patient is assimilating the information during the medical encounter; (ii) the perceived (by the physician) nature of the physician-patient relationship; and (iii) the oncologists' assessment of the role they should take in the treatment decision making with each patient (i.e. directive, a shared role with the patient, a more passive role in which the physician gives options and the patient makes the decision). These subthemes appear to be interrelated and not independent of each other.

The oncologist's on-going assessment of how the patient is following or assimilating the information shared during the medical encounter
Oncologists described several factors that influence what information they share during the medical encounter. Many oncologists mentioned that they perceived that a woman's emotional state influences her ability to assimilate information and this in turn influences what information the oncologist shares.

It depends on the timing...sometimes you'll say all the information and then they'll break down at the end...you have to have at least some acknowledgement...did she retain what was said. Where others I say well you know you're cancer has come back and they start bawling so then, so in that situation you may not be able to get in as much ...information. You try but you may temper it. (Participant 1)

Given that many oncologists described tailoring the information, we focused on strategies the oncologists used to determine whether the patient was following what information was shared.

Oncologists reported that the questions the patient asked is a way to gauge how informed or how insightful a patient was. The oncologists also described using questions as the responses provided the oncologist with an appreciation for what was important to the patient, her expectations and her goals for further management. Thus, a patient's response to specific questions influenced what type of information was then provided.

The questions they would ask or the comments they would make were more in keeping with the bigger picture. Okay I can live through that, what would happen after that? Or what if I don't do this? You know actually asking about the disease and the implications of treatment or the likelihood of responding to a treatment or tolerating the treatment. So the interaction in terms of their sophistication, so they've already got the nuts and bolts but they wanted the bigger picture. What happens then or what does it mean if I don't do this or who else will I see. Whereas, the other patient it was we never got to that level that next level of sort of the broader picture because we couldn't get out of the details... That's an example of my use of my perception of a person's ability to understand. (Participant 15)

Some of the oncologists indicated that when discussing outcomes information, some patients just did not want to know certain things (such as median survival). A couple of the oncologists described asking the woman for her permission whether or not to discuss outcome information. These oncologists reported that they felt this technique of asking for permission provides the patient with a sense of control and minimized her anxiety.

The oncologists' perception of their relationship with the patient

Oncologists' perceptions of their relationship with the patient in any given medical encounter influenced what information was exchanged. For example, most oncologists indicated that

when they met a patient for the first time, they spent more time in the interaction. In part, this involved building a rapport with the patient.

I spend more time initially because I think that's important. I think if you invest that time initially you can, I mean you still need time to divulge information but you can be a lot quicker because you've made that relationship. ... Trying to establish that relationship the rapport. (Participant 1)

Most of the oncologists described that the nature of the interaction with the patient differed depending on whether the patient was from the physician's practice vs. a patient for one of their partners' practices. The interaction with the patient from the physician's practice was reported as being a more focused or concise. The interaction with a patient of one's colleagues was characterized as taking more time to understand what the patient understood about her situation and ensure they (the oncologists) understood the patient's medical and social context and taking this time they believed served to build trust.

Well usually you go in the room and if, we have a group practice so you know the patients don't always kind of I don't think they know who we are. So you know introduce myself and then sit down and I sort of ask them how they're doing. If they've either been on chemo and they've progressed or they've been off, you know just how are things going? How do you feel? (Participant 6)

Oncologists reported that other members of the health-care team participated in the woman's care and shape the information exchange. Interactions with members of the health-care team on the telephone preceding the appointment or just the booking of an unscheduled doctor's appointment force the patient into a mode of questioning or pondering. This process influences what information is shared in the medical encounter.

I work as part of a team. I have a nursing colleague who does most of the legwork in terms of having things prepared for the patients to come... just a very general thing she probably has said on the telephone to that person in terms of coming back to see Dr X. It has probably

stirred up some concerns in their mind that these are the things that are coming. So people don't generally walk in completely 'oh my god' about things. (Participant 4)

Oncologists reported that the physician-patient relationship was influenced by family members and that relatives figured prominently in what information was shared. The oncologists reported that these relatives appeared to hear the information with more emotional distance compared to the patient. Again, oncologists perceived that the accompanying person processed the information faster and brought up important issues or asked key questions. In addition, the oncologists indicated that the accompanying person has a better understanding of the patient's context in terms of home life and ongoing social issues compared to the health-care team. The relative(s) acted as a coach or mentor after the medical appointment and reinforced the messages delivered during the interaction and helped the patient process the information.

Well I find out who is in the room first of all. If it's family or friends. And at some point, I often ask can we talk openly in front of everyone so with their permission. And that's ok that's a good thing because if you get a phone call from them you've already said, the patient has already told you, you can talk openly, you can communicate with them. (Participant 1)

Culture and language differences sometime complicated the physician-patient relationship and the information exchange. The value of having a non-family member relay the physician's message was articulated by one of the oncologists:

Well first of all if it was language I would never give information through a family member. I always have an interpreter which may seem very obvious but it can be hard to organize that but it is important because you have no idea. Two things you have no idea what information that they're giving the patient and second of all it puts that family member in a very difficult position to tell bad news. (Participant 14)

One example of such a medical encounter was when it became clear that the family had withheld the diagnosis of cancer from the patient.

The whole information sharing about treatment stopped until this misperception was dealt with.

I then talk to the family and just say you know what she's not ready to hear the cancer word today these are the tactics we can use. You can either you know go home and then I discuss with them how they should approach it with mom. If they say it would be a lot better at home when we can sit around the table and my brothers and sisters will be there kind of thing. I say Ok but then when we come back next week she needs to know because otherwise we can't move forward. I'm very adamant about that. Secondly they and then often when I explain to the family members she has to know because I can't be getting consent for an operation if she doesn't understand what she has... So often for you know reasonable people then that will kind of get them over the hump and then I say to them you know we do have to tell her. (Participant 14)

Trust within the physician–patient relationship was also reported as influencing what information the physician perceives that the patient wants and the role the patient wishes to take in the treatment decision-making process.

If I sense that there is absolutely no other option, we should try it because there's a high chance of success and you have to and the patient is a little reluctant then I might explore why and also say well you know I really, really would like you to reconsider and have this option because I really think it's needed. Otherwise you know the other options do nothing and you know you may only have a few weeks if that's the case. But sometimes the patients provide options and they'll come up and say 'what would you do?' 'What do you really recommend?' ... So then you help a little more by, because they don't want. I think indecision can create a lot of anxiety as well. So sometimes they will ask for clarification and that's ok. If there are 2 equal options then I find it's harder but it's not unmanageable. And with dialogue it may take 2 sessions or longer sometimes but most will come to a decision that they're comfortable with. At the end some will say 'doc I'm confused you make the decision' then I say 'well then I would favor this.' So I don't leave them in a lurch. (Participant 1)

Oncologists' assessment of what role they should take in decision making

The oncologists commented that whether they gave treatment options or a specific treatment

recommendation depended on how they perceived their role in treatment decision making.

I do make recommendations. You know if it's their fourth line of treatment and I suspect they're not going to respond and I think they've got a month left to live my recommendation in those cases would be not to get treatment but rather to try and enjoy the time that they have left and find out what's really important for them and how can we work together to obtain those goals. So yeah I mean that's the part of the art of medicine I think. (Participant 13)

Whether a recommendation was given appeared to be oncologist dependent. Some oncologists reported that they always gave a recommendation. Other oncologists reported only providing a treatment recommendation if the patient requested this. Giving a treatment recommendation appeared to be influenced by the oncologist's assessment of the patient's capacity to sort through the information and come to a treatment decision. The oncologists did not articulate asking the patient about her preference for her role in the interaction and/or the oncologist's role in decision making.

In summary, the oncologists reported that what information is shared during the medical encounter is influenced by the oncologist's assessment of the situation, the oncologist's assessment of the physician–patient relationship and the oncologist's assessment about their own role in decision making. These assessments appear to be subjective. The oncologists did not refer to any objective tools that helped validate their assessments. There was no report of any independent assessment of the oncologists' impression as a check or balance to the oncologist's impression.

Theme 3: factors that influenced how information is given

When the oncologists were specifically asked about cues that influenced how the information is exchanged, the oncologists became silent. However, the oncologists' stories clearly described implicit criteria that influenced how they said what they said to patients.

Oncologist's perception of patient's vitality (or functioning)

Patient's vitality, performance status, other comorbidities along with information about the patient's prior tolerability of chemotherapy were reported as influencing how the information is shared and whether the oncologist gave a treatment recommendation.

I'm very respectful of age. I have a patient who's 85 years old and she's got recurrence and she's asymptomatic and she's very active and we just talked about the fact that she is very active and why would she want to go back on chemotherapy now when she feels good and is able to do things. I think in the same manner for someone who is quite young who is in their 40s I would tend to, quite often those patients come in and want everything to be done and they want us to be very aggressive and I would be very supportive of that approach as well. So I mean I think with every patient you have to sort of size it up.

If we're talking about an 85 year old whose had a hard time with the chemotherapy and now it's recurred at 3 months well that's a different discussion than the 49 year old who has children at home and has recurred within 3 months and still is going to be very keen on getting further treatment. (Participant 13)

The patient's overall health status influenced the type of information, detail of information and treatment recommendation provided.

I think if people's overall health status is really bad I would probably suggest a slightly different course. (Participant 11)

Oncologist's perceptions of patient's comprehension of the information

The oncologists indicated that a patient's educational level and the oncologists' perception of the patient's ability to process concepts also influenced how the oncologist shared information.

I mean I think a patient's education is a major part of, their general education. I mean I think there are some people who are very educated and usually that patient is very well informed and they want finer details than just the big picture. Whereas people, who may not be as educated,

aren't, they're not gathering information for themselves so they're coming at a very basic level and they're requiring the basic information the big picture of what's happening. (Participant 13)

People who or who don't seem to understand the concept of response rates. You know people who keep on repeating 'is it going to work or not?' If it's not a black and white answer you can't answer. So sometimes they're you have to kind of word it so they can understand. (Participant 12)

A few oncologists mentioned that a woman's perceived mental acuity influenced how they shared the information.

If I don't feel they can make their own decisions, like she was mentally challenged, then I would present it in a different way. I would probably make it a little bit more simplified the whole decisions and not getting too detailed with the names of the drugs and things like that. (Participant 11)

In order to assess the woman's comprehension of the concepts discussed, oncologists described different techniques such as using questions to help discern what information to share and how to frame it. In the situation where the patient misunderstood the information, oncologists reported that they either repeated the information or framed the information in a different way. When an oncologist perceived that a patient did not understand the information, or if it was not clear whether the patient understood the information, the oncologist reported that reframing the information improved the woman's comprehension.

Oncologist's perceptions of patient's demeanour or emotional well-being

Most of the oncologists described tailoring the information based on their perceptions of patient's demeanour. Specific cues included being tearful, weeping, poor eye contact, raised voice or a blank stare.

....if they look like they are distracted, if they look like they're disconnected in the moment from the conversation, if I see that in any of their family members, if they express anger, if they express an emotional reaction that's intense,

if they seem bewildered, if they start to break down and cry, if I see any emotional intensity I'll check in with them and pause. And I'll ask them how they're doing. I ask permission to be frank with them before I just start being frank with them. And if they look like they're not doing well, I ask them you know if they need to take a break. (Participant 10)

Some oncologists described that when they perceived that a patient was very emotional, then they streamlined the amount of information providing small sound bites.

I can sense either from their demeanor or their eye contact or their emotional state at the time I really know that the uptake isn't as good and I can only give them limited bits of information I don't necessarily elaborate as much. (Participant 16)

Often in this scenario, oncologists described offering the patient an opportunity to return at another time to discuss the information.

Oncologist's perceptions of making information relevant for the patient

One oncologist said that he tries to explain the information from a perspective that is relevant to the patient.

I try and tailor the information to them as an individual person in ways that I think they can relate to. Meaning that I try and use analogies that they would understand from their own profession if I can come up with such an analogy or relate it to a personal experience in their own life. (Participant 4)

Oncologist's perceptions of patient- or family-initiated questions

The information exchange was guided by the questions a patient or her family asked.

You know again I think their level of understanding is based on the questions they had for you throughout the encounters you had with them. So if they're asking a very detailed question or you know allows you to know that they have a very good understanding of what's going on. And again that's going to be different with a patient who doesn't really ask a lot of questions or when you ask them you know, they say oh I understand I have this and can you treat it? (Participant 13)

Competing demands for the oncologist

All the oncologists indicated that there were external factors that influenced the depth and breadth of information they shared with patients. (Here, we have some overlap of themes 1 and 3.) For example, time constraints in the clinic (too many patients to see in a given time and space) or competing time demands on the physician (i.e. meetings, operating room schedule) were seen as factors that curtailed the amount and type of information shared. The setting for the information exchange was seen as important. Sharing information in a four-bed hospital ward room or a busy waiting room limited the amount of information that physicians reported providing. Usually, a private office setting was felt to be most conducive to an unhurried exchange of information and decision making.

Discussion

In the treatment decision-making encounter with women who are experiencing their first recurrence with ovarian cancer, the oncologist is the one who has the knowledge about the disease (i.e. exact diagnosis, potential treatment options, their potential benefits and side effects). The patient depends on the oncologist to share this information in order to be informed and participate (if she wishes) in making a treatment decision. Thus, it is important to understand whether the oncologists give the same information to all their patients. If oncologists do not give the same information to all patients, what are the factors that influence what information is given and how that information is given? There is little information in the literature on this topic. In this paper, oncologists who treat women with recurrent ovarian cancer described from their perspective that they do not give all women the same information. All the oncologists in our study said they provided some information in the following domains: status of the disease, treatment options and side effects of treatment. However, they differed in the amount of information

shared and the way in which it was shared in the domains mentioned. The oncologists described two styles in which the information was shared. The most common style was being straightforward. A much less common style involved using analogies to clarify for the patient concepts such as metastasis. The oncologists indicated that the choice of what information was shared was influenced by the oncologist's perception of how the patient was assimilating information, the oncologist's relationship with the patient and the oncologist's assessment of what role they (the oncologist) should take in treatment decision making. How information was given was influenced significantly by the oncologist's perception of the patient's vitality, the patient's comprehension of the information and the patient's emotional well-being. The oncologist used patient questions to direct how much information they shared. Information was tailored or reframed or analogies used to clarify the information. Other demands on the oncologist (i.e. schedule conflicts) or the environment in which the oncologist met the patient (i.e. four-bed ward room vs. a private clinic room) influenced how information was shared.

That gynaecologic and medical oncologists provide women with recurrent ovarian cancer information in the domains described above meets the requirements for communication put forward in the Ontario evidence-based recommendations about how clinicians can communicate effectively with patients.^{10,11} However, there is a repeated finding in this study that much of the depth/breadth of information and how the information is shared depends on the subjective 'perceptions' of the oncologist. There is very little published literature addressing the accuracy of oncologist's perceptions of patient's preference for receiving prognostic information, the accuracy of oncologist's perception of patient's preference for participation in decision making and how these perceptions influence the breadth/depth of information the oncologist gives to patients about their disease, treatment options and risk during the medical encounter. In one study, Elkin *et al.*¹² showed

that 61 patients with advanced colorectal cancer were asked about their preference for prognostic information and for decisional control in advance of the medical encounter. In only 44% of these cases did the oncologist accurately predict the patients' desires for prognostic information (κ : -0.11; 95% CI: -0.35 to 0.14), and in only 41% of these cases did oncologists accurately predict patients' preference for decisional control (κ : 0.04; 95% CI: -0.13 to 0.22). Similar discord between patient preference for decisional role and physician perceptions has been reported in 57 patients with breast cancer. Forty per cent of the women had metastatic breast cancer. In only 42% of the 57 patients did the medical oncologist accurately predict the woman's decision-making preference on a seven-point descriptive scale.¹³ These findings suggest that the oncologists' perceptions of patients' desires for information and/or participation in decision making may not be accurate.

In keeping with our results, the literature also showed that oncologists' preconceived ideas about the impact of patient's age or socioeconomic status on the patient's ability to understand the information influenced whether and how the oncologists tailored information on treatment options that was given to the patients in their practice. For example, Step *et al.* conducted a cross-sectional observational study of medical oncologists communicating with their 40- to 80-year-old patients with breast cancer. The study results showed that oncologists communicated with older patients in a more direct, slower manner than they did with younger patients. They gave older patients a single treatment recommendation while giving more than one treatment option to younger patients.¹⁴ In another study, 24 Caucasian oncologists were found to provide tailored information to patients who they perceived to be of lower socio-economic class. These oncologists also gave these patients fewer treatment options than patients who were perceived to be of higher socioeconomic class. It was not clear whether this finding was related to oncologists' concern about patient's ability to pay or some

other factor.¹⁵ Douma *et al.* assessed 150 consecutive patient and radiation oncologist interactions to understand oncologists' information-giving behaviour. Prior to the interaction, patients identified their information needs using a 35-item questionnaire. The information provided by the oncologists matched the patients' information needs in 50.8% ($\kappa = 0.07$).¹⁶ More research on defining oncologists' perceptions and their subsequent information-giving behaviour during the medical encounter is needed to understand how this can influence patients' choice of treatment.

In our study, the oncologists did not describe using other ways of providing information (such as the Canadian Cancer Society or Ovarian Cancer Canada brochures, a list of highly regarded disease-specific websites such as the National Cancer Institute) or tools (such as a decision aids²) to ensure that all women received the same core information. More importantly, the oncologists did not describe any objective means such as a standard set of questions to determine what information the patient wanted, or patient comprehension of the information provided. Nor did the oncologists make attempts to determine patient's desired role in decision making.

There are training programmes that are aimed at optimizing physician–patient information transfer and treatment decision making in the medical encounter. Legare *et al.*¹⁷ conducted an environmental scan and described 54 programmes of which the majority focused on licensed health professionals and the rest on pre-licensure health professionals. Five programmes covered the domain of cancer,^{18–21} and three involved palliative care. These training programmes in shared decision making provided printed educational materials, case-based discussions, role play and audit and feedback as a means of developing communication skills (i.e. the solution). However, what our paper shows is that unless we understand what influences what and how oncologists communicate (i.e. the problem), these programmes may not correct the dissonance between the information patients need for

making a treatment decision and the information they receive. In other words, we need to understand the problem, in this case what influences what oncologists say and how they say it and then create the solution (training programme).

Our study suggests that an oncologist's perceptions of the patient's demeanour and interaction during the medical encounter are key in influencing the information that the oncologist relays to the patient. Further, our research suggests that these perceptions influence what information the oncologist shares with patients and how that information is communicated. Future research will need to make explicit these perceptions, their origins and how they influence the oncologist because what information the oncologist shares with the patient influences her treatment decision.

The results of this study must be seen within the context of its limitations. Firstly, our sample size was 20 oncologists of a potential 38. It must be pointed out that of the invited medical oncologists, some may not have participated as they may not have met the self-assessment criteria of having a practice of which one-third consisted of ovarian cancer patients. Thus, the denominator of eligible oncologists may be lower than 38 and thus the response rate higher. Importantly, the sample size of 20 oncologists did allow us to reach the study's objective (to explore from the oncologists' perspective, information giving to women at the time of their first recurrence with ovarian cancer). There is precedent in the qualitative literature for studies of small sample sizes. The intent in qualitative research is not to generalize the information, but rather to collect extensive information about each site or individual studied in order to obtain information-rich data that will promote them saturation.^{4,22} A second limitation of this study is that what oncologists' report as their practice may be different from what they actually do at the bedside. However, we believe that the results from this study are still pertinent as perceptions of reality reflect how oncologists think about the issues of communication and how they intend

to behave during the medical encounter. The ideal research situation would be to have both self-reported and observational data so that the two could be compared for discrepancies.

WI Thomas in co-operation with Florian Znaniecki developed the Thomas theorem, a fundamental tenet of sociology that says 'If men define situations as real, they are real in their consequences'.²³ The issue that this paper highlights is how oncologists' perceptions about characteristics they attribute to their patients influence their (oncologists) behaviour in communicating with these patients about treatment options and their benefits and risks. What is unknown is the extent to which these oncologists' perceptions actually reflect their patients' self-identified information and decision-making needs. What is also unknown is whether oncologists actually provide the information they indicate they provide or whether what they reported is the ideal that they either believe or what they sensed the researchers were looking for. One way in which these issues could be addressed is by direct observation of the medical encounter right after the diagnosis of the first recurrence of ovarian cancer is made when information is given. Then, each party could be questioned separately to assess comprehension and perceptions. To the extent that discordance is found to exist, strategies are needed to better identify and communicate patients' information and decision-making needs to oncologists and to assess whether these needs are being met.

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Conflict of interest

There are no conflicts of interest to declare.

References

- 1 Elit L, Charles C, Gafni A, Randford J, Tedford Gold S, Gold I. Walking on a tightrope: the

- oncologist' perspectives on providing information to women with recurrent ovarian cancer during the medical encounter. *Supportive Care in Cancer*, 2012; **20**: 2327–2330.
- 2 Donovan KA, Greene PG, Shuster JL, Partridge EE, Tucker DC. Treatment preferences in recurrent ovarian cancer. *Gyn Oncology*, 2002; **86**: 200–211.
- 3 Willis J. *Foundations of Qualitative Research: Interpretive and Critical Approaches*. Thousand Oaks, CA: Sage Publications, 2007.
- 4 Creswell JW. Choosing among five traditions. In: Creswell JW (ed.) *Qualitative Inquiry and Research Design*. Thousand Oaks, CA: Sage Publications, 2007: 85–99.
- 5 Huberman AM, Miles MB. Data management and analysis methods. In: Denzin NK, Lincoln YS (eds) *Collecting and Interpreting Qualitative Materials*. Thousand Oaks, CA: Sage Publications, 1998: 179–210.
- 6 Strauss AL, Corbin JM. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*, 2nd edn. Thousand Oaks, CA: Sage Publications, 1998.
- 7 Miller W, Crabtree BF. Primary care research: a multi-method typology and qualitative road map. In: Crabtree BF, Miller WL (eds) *Doing Qualitative Research*. Newbury Park, CA: Sage Publications, 1992: 17–21.
- 8 Kaczynski D. Examining the impact of qualitative data analysis software upon the analysis process. Paper presented at the Australian Association of Research in Education. Melbourne, Australia, 2005. Available at: <http://www.aare.edu.au/04pap/kac041065.pdf>, accessed 1 September 2001.
- 9 Weitzman EA. Software and qualitative research. In: Denzin NK, Lincoln YS (eds) *Collecting and Interpreting Qualitative Materials*. Thousand Oaks, CA: SAGE Publications, 2003: 310–339.
- 10 Rodin G, Zimmerman C, Mayer C *et al.* Evidence based recommendations to guide clinical practice in cancer. *Current Oncology*, 2009; **16**: 42–49.
- 11 Rodin G, Mackay JA, Zimmermann C *et al.* Clinician-patient communication: a systematic review. *Supportive Care in Cancer*, 2009; **17**: 622–644.
- 12 Elkin EB, Kim SHM, Casper ES, Kissane DW, Schrag D. Desire for information and involvement in treatment decisions: elderly cancer patients' preferences and their physicians' perceptions. *Journal of Clinical Oncology*, 2007; **25**: 5275–5280.
- 13 Bruera E, Willey JS, Palmer JL, Rosales M. Treatment decisions for breast carcinoma: patient preferences and physician perceptions. *Cancer*, 2002; **94**: 2076–2080.
- 14 Step MM, Siminoff LA, Rosa JH. Differences in oncologist communication across age groups and contributions to adjuvant decision outcomes.

- Journal of the American Geriatric Society*, 2009; **57**: S279–S282.
- 15 Pollack KI, Alexander SC, Grambow SC, Tulskey JA. Oncologist patient-centered communication with patients with advanced cancer: exploring whether race or socioeconomic status matter. *Patient Education and Counseling*, 2010; **24**: 96–98.
- 16 Douma KFL, Koning CCE, De Haes HCJM, Zandbelt LC, Stalpers LJA, Smets EMA. Do radiation oncologists tailor information to patients needs? And, if so, does it affect patients. *Acta Oncologica*, 2012; **51**: 512–520.
- 17 Legere F, Politi MC, Drolet RM *et al.* Training health professionals in shared decision-making: an international environmental scan. *Patient Education and Counseling*, 2012; **88**: 159–169.
- 18 Diefenbach M, Turner G, Carpenter KM *et al.* Cancer and Patient-Physician Communication. *Journal Health Communication*, 2009; **14** (Suppl. 1): 57–65.
- 19 Roter D, Larson S. The Roter interaction analysis system (RIAS): utility and flexibility for analysis of medical interactions. *Patient Education and Counseling*, 2002; **46**: 243–251.
- 20 Amalraj S, Naeim A, Nguyen C, Starkweather C. Health literacy, communication and treatment decision-making in older cancer patients. *Oncology*, 2009; **23**: 369–381.
- 21 Bragard I, Razavi D, Marchal S *et al.* Teaching communication and stress management skills to junior physicians dealing with cancer patients: a Belgian Interuniversity Curriculum. *Supportive Care in Cancer*, 2006; **14**: 454–461.
- 22 Kuzel A. Sampling in qualitative enquiry. In: Crabtree B, Willer W (eds) *Doing Qualitative Research*. Thousand Oaks, CA: Sage publishers, 1999: 33–45.
- 23 <http://www.newworldencyclopedia.org/entry/W.I.Thomas>, accessed 23 November 2011.