

WHAT WE KNOW ABOUT TREATMENT DECISION MAKING IN OVARIAN CANCER

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Resumen

Objetivos: exponer lo que se conoce acerca de tres niveles de toma de decisión sobre tratamiento en el encuentro médico: (1) intercambio de información, (2) deliberación, y (3) toma de decisión en el cáncer ovárico.

Métodos: Se completó una búsqueda bibliográfica que incluía investigación original acerca de la toma de decisión del tratamiento médico sobre el proceso de enfermedad del cáncer de ovario.

Resultados: el intercambio de información mostró que los pacientes y los médicos sienten que la expectativa de vida es el tema más importante. Los médicos informan que no discuten esto en el diagnóstico inicial. Las ayudas a la decisión pueden emplearse como una herramienta para asegurar la información. El nivel de deliberación es el menos investigado. No hay información sobre el rol que los pacientes y médicos toman. Con la excepción de una herramienta basada en Internet, no hay investigación sobre como elicit las preferencias del paciente. Durante la toma de decisión del tratamiento, las mujeres no perciben que ellas tengan opciones de tratamiento aunque sienten que están tomando una decisión. El "no tratamiento" no se considera una opción.

Conclusiones: la toma de decisión sobre los tratamientos en cáncer de ovario esta progresivamente siendo valorada. El nivel de intercam-

Abstract

Objectives: To describe what is known about the three stages of treatment decision making (TDM) in the medical encounter: (1) information exchange, (2) deliberation, and (3) making the treatment decision for ovarian cancer (OC).

Methods: A literature search was completed including original research on TDM as it pertained to the disease continuum of OC.

Results: Information exchange shows that patients and physicians feel that life expectancy is the most important issue. Physicians report that they do not discuss this at initial diagnosis. Decision aids could be used as a tool to ensure that information. The deliberation stage is the least researched. There is no information on the role that patients and physicians take. With the exception of one internet based tool, there is no research on how to elicit patient preferences. During making the treatment decision, women do not perceive that they have treatment options yet they feel they are making the decision. "No treatment" is not considered to be an option.

Conclusions: TDM in OC is increasingly being evaluated. The stage of information exchange has been assessed in greater depth compared to that of the other stages.

Key words: Ovarian Cancer, Decision Making.

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bio de información ha sido evaluado en mayor profundidad comparado con otros niveles.

Palabras clave: Cáncer de ovario, toma de decisión.

Introduction

Globally, ovarian cancer accounts for 3% of all cancers in women. Worldwide it has an age standardized incidence rate of 6.3 per 100,000 and a mortality rate of 3.8 per 100,000 women. Ovarian cancer has the highest mortality rate of all cancers of the female reproductive system⁽¹⁾. Of those women who are diagnosed with ovarian cancer, 70% will die of their disease. If the cancer is limited to the ovary, then on average a woman's 5 year survival is 80%; however, only 23% of women present with localized disease. Most women who have ovarian cancer are diagnosed when the disease is widespread/advanced; their average survival rate at 5 years is less than 20%.

Usually when a woman seeks medical attention, she has symptoms of abdominal bloating, pelvic discomfort or abnormal vaginal bleeding. This woman already has advanced disease. Once the diagnosis of possible ovarian cancer is made, there are a series of treatment decisions to be made. If the woman presents with an isolated mass, one treatment decision is whether to have her surgery by laparotomy (large incision) or laparoscopy (using 4 or more very small incisions and a camera). The goal of surgery is to make a histologic diagnosis, identify the extent of disease spread and to remove as much tumour as possible. There are pros and cons with either route of accessing the abdominal cavity.

Once ovarian cancer is histologically confirmed, the goals of care become control of symptoms and prolongation of life. Thus the decision at this point in the journey involves whether or not the

woman agrees to using chemotherapy, which agents and whether this will be by an intravenous or intraperitoneal route. A variety of drugs are available and these can be used alone or in a number of combinations with varying effectiveness. Both the access route for administering the drug and the drug chosen have unique potential side effect and potential benefit profiles.

Ovarian cancer has a variable course characterized by initial response to chemotherapy often followed by relapse and progression of disease. When the disease recurs, the woman will always live with disease. From time to time she is likely to have complications related to the disease or the treatment. Eventually she will die of her disease. At the time of disease recurrence, the woman needs to decide if she wishes active management of the tumour with further chemotherapy or clinical trials (assessing novel agents), or focus on symptom management alone. In summary, management of ovarian cancer throughout the cancer journey from diagnosis to death can impact quality of life^(2,3), symptoms and psychological well-being⁽⁴⁾.

Stages in Decision Making

A recurring theme in the ovarian cancer journey is the necessity of making a treatment decision at different points in the disease continuum. For the sake of this manuscript, treatment may refer to surgery, chemotherapy or symptom management only. After a review of the patient's story, physical exam and tests results, the patient and physician meet together to determine

the most appropriate treatment. This process typically involves three stages: 1. Information exchange about disease management, 2. Deliberation or eliciting patient (and in some cases, physician) values and preferences about the treatment options and, 3. Making a decision about the treatment to implement⁽⁵⁾ (Table 1).

Information exchange is the relay of information usually from the physician to the patient but it can be from the patient to the physician. The content and extent of the information exchange may vary depending on the type of encounter but for the purposes of this discussion, the information exchange should provide at minimum the disease and treatment related information for making a treatment decision. *Deliberation* is the process of identifying values (i.e., what is important for that individual – patient and/or physician) and expressing and discussing treatment preferences. *Making the treatment decision* can be something the physician or patient does alone or can involve both parties. Making a decision implies that there are treatment options.

In this paper we will discuss what is known about the three stages of treatment decision making (i.e., information exchange, deliberation including the process of eliciting patient preferences and making the treatment decision) in the context of ovarian cancer. Each stage will be discussed along the continuum of the ovarian cancer journey from onset of symptoms, through diagnosis, initial treatment, recurrence and palliation.

METHODS

A literature review was conducted using Medline and Google. The key words included: treatment decision making, information exchange, communication, preferences, and ovarian cancer. We retrieved 260 abstracts in the English

language. Manuscripts were retrieved if the abstract indicated that the article described original research on the treatment decision making process in women with ovarian cancer. Manuscripts were excluded if they 1) were written in a language other than English, or 2) were comprised of non-original research. Each manuscript was read and the contents summarized. This included: study population, study objectives, study type, results, and information about any of the 3 stages of decision making. The results were grouped according to the information they provided about one of the 3 stages of decision making. The information on each stage was summarized and then on several occasions discussed with the chapter authors.

Findings

Specific research themes addressed in the literature on **information exchange** include: 1) reason for information seeking, 2) the kinds of information that patients and their physicians think are important for patients to receive in the medical encounter, 3) satisfaction with the information exchanged, 4) the kinds of information that ovarian cancer specialists communicate to patients in the medical encounter, 5) the information women hear during the encounter, 6) physician communication styles, and 7) physician's use of decision aids to communicate information on treatment risks and benefits to patients. Research themes related to the process of **deliberation** about treatment options in the medical encounter include: 1) the role patients want in TDM, 2) the values of women with ovarian cancer, 3) their treatment preferences, 4) Physician's treatment recommendation, and 5) factors that aid in the deliberation. Research themes pertaining to **making the treatment decision** include: 1) the range of options discussed, 2) women's perceptions about

Table 1. Survey of papers on ovarian cancer and information exchange or treatment decision making

ROC – Recurrent ovarian cancer						
	Donovan ⁽²³⁾	Elit ⁽¹⁰⁾	Elit ⁽¹⁸⁾	Elit ⁽¹³⁾	Feldman Stewart ⁽⁹⁾	Finn ⁽⁸⁾
Year	2002	1996	2003	2009	1996	2000
Type of Study	4 Questionnaires Preferences Exercise	Series of studies 1. Instrument testing 2. Instrument application 2. Questionnaires	Individual interviews	Individual interviews	Questionnaire	Individual interviews
Point in the journey	First line ovarian cancer	Initial chemotherapy for ovarian cancer	Initial chemotherapy for ovarian cancer	First recurrence	Any	ROC
Focus	Preference for tx with ROC	Preference for treatment	Extent to which women understood they had tx options, benefits and risks of tx and role in DM	Extent to which women understood they had tx options, benefits and risks of tx and role in DM	Define standards for provision of information to ovarian cancer patients	Describe the lived experience of women with ovarian cancer
Population	81 women with Ovarian cancer receiving first line treatment 75 Non-cancer cocontrols	37 Volunteers 11 Women who had completed chemotherapy for ovarian cancer 13 at point of deciding for Initial chemotherapy for ovarian cancer 6 MDs	21 Women	26 Women	83 women with ovarian cancer 20 volunteers 116 MDs	6 women
Geography	Birmingham Alabama, USA	Hamilton, London Canada	Hamilton, London Canada	Hamilton, Canada	Canada	Hamilton, Canada

Author	Fitch⁽³²⁾	Fitch⁽¹⁴⁾	Fitch⁽⁶⁾	Howell⁽¹⁵⁾	Howell⁽³³⁾	Jolicouer⁽¹²⁾
Year	1999	2002	2003	2003	2003	2009
Type of Study	Survey	Individual telephone interviews	Individual Telephone Interviews	Individual Telephone interviews	Individual interviews	Individual interviews
Point in the journey	Any	Any	Any	Any	First recurrence	ROC
Focus	Experience living with Ovarian Cancer	Diagnosis of ovarian Cancer	Treatment and treatment decision making	Experience of living with ovarian cancer	Experience of living with ROC Tx -treatment	Describe decision making needs of women with Ov Ca
Population	315 women with ovarian cancer	18 Women with ovarian cancer	18 Women with ovarian cancer	18 women with ovarian cancer	18 women with ROC Tx-treatment	15 Women on chemotherapy for platinum sensitive ov Ca
Geography	Canada	Canada	Canada	Canada	Canada	Ottawa, Canada

Author	Stewart⁽¹¹⁾	Zieband⁽¹⁶⁾
Year	2000	2006
Type of Study	6 survey tools	Individual interviews
Point in the journey	Any	Any
Focus	Information needs, Decision making role, Influencers	Involvement in treatment decision making
Population	139 women with ovarian cancer	43 women with ovarian cancer
Geography	Canadian	United Kingdom

ROC – Recurrent ovarian cancer

no treatment as an option, 3) how the treatment decision is made, and 4) factors that appear to influence the treatment decision.

1. Information Exchange

We usually expect that the direction of information exchange in the medical encounter is predominantly from the physician to the patient. However, especially in this era of access to the internet, second and third medical opinions, this process could also involve the patient bringing information either about her disease or other management strategies to the physician. Thus information exchange encompasses not only the flow of information but the direction, the type of information and the amount of information.

1.1. Reason for information seeking

Research suggests that women with ovarian cancer want information about their disease and its treatment for several reasons; it will help them cope better with treatment side effects⁽⁶⁾, or to enhance their psychological autonomy⁽⁷⁾. Some authors point out that women want information regardless of their desire to be responsible for making a treatment decision^(7,8). For the purpose of this paper, we will try to focus on the kind of information a patient requires in order to make a treatment decision.

1.2. Kind of information

The “kind” of information involves not only the type of information but also whose perspective is important in identifying what information should be exchanged. The ovarian cancer literature provides some insight into these questions from the perspectives of the patient, society and physician. In a study of the medical encounter in the context of ovarian cancer

conducted by Feldman Stewart in Canada in 1996⁽⁹⁾, eighty three women with ovarian cancer, twenty volunteers who did not have cancer, and one hundred and sixteen physicians were asked to rate the importance of 57 questions in terms of whether they should be discussed during the medical encounter. Importance was indicated on a 100 mm visual analogue scale anchored by “not important” on the left to “very important” on the right. The patients and volunteers felt that information related to life expectancy was most important (median 92.1 and 96.2 respectively). The patients and volunteers felt that issues of cost of treatment were least important (median (rank) 47.0 (57) and 50.0 (55) respectively). In part this may reflect the fact that in Canada, cancer treatment is publicly funded. The patients and volunteers were congruent in ranking what were high and low priority topics of information exchange.

In this study, the Canadian physicians who actively manage women with ovarian cancer in major cancer centres completed the same questionnaire. The physicians also felt that information related to life expectancy was most important (median 88.4 physicians) and they concurred that issues of cost of treatment were least important (median (rank): 16.5 (57) physicians). The physicians felt that information on diet was not important in contrast to patients; patients felt that information on sexual attractiveness was not important in contrast to physicians. On the most important and least important issues to be discussed in the medical encounter, all three groups agreed. On other issues, the patient and volunteer groups were more similar in their views than were either to the physician group.

Elit (1996)⁽¹⁰⁾ conducted a study of six physicians after observing a medical encounter at the point on making a treatment

decision for *first line chemotherapy*. All physicians indicated that the encounter should include information concerning the patients' disease status, available management options, chemotherapy, treatment process, and potential side effects. Physicians indicated that they would not give patients survival information at this point in the cancer journey unless the patient specifically asked. Those same physicians said that if they were the patient, they would want survival information. When asking 48 women whether survival information should be discussed, both women without cancer and women who had already received first line chemotherapy for ovarian cancer advised that the physician should ask the patient whether or not she wanted to hear the survival information⁽¹⁰⁾. Some women indicated that prefer not to hear this information.

Stewart 2000⁽¹¹⁾ surveyed 139 Canadian women at *any point in the ovarian cancer journey*. Six different questionnaires were used to obtain demographic information, psychological functioning, preferences, and specific information needs. These women wanted information on the status of their cancer (is there cancer in their body, how will they know if it has come back), treatment concerns (what are the various treatments recommended for this cancer and how successful are they), and self care and empowerment (what they could do to improve their recovery). These information preferences were stable across the illness trajectory.

Factors that influenced the kind of information patients wanted have been described by several authors. In this same study⁽¹¹⁾, she identified that higher education levels were positively related to preferences for more detailed information among study participants ($p < 0.05$). Older woman (age over 60 years) sought out information focused on physical aspects of her health ($p < 0.05$). The literature

suggests that the type of information that women with ovarian cancer want may be influenced not only by the woman's age and level of education, but also prior experience with health care issues^(10,12), personal experience with disease⁽¹³⁾, anxiety⁽¹⁴⁾ and depression.

1.3. Satisfaction with information exchange

To understand whether patients are satisfied with the information given in the medical encounter, Fitch conducted a cross-sectional survey of 315 Canadian women living with ovarian cancer^(6,14). Eighty percent of women felt adequately informed and were satisfied with communication with their physician (mean 4.1-4.5 out of 5 point scale). The information they felt was most important to have was information about their particular situation with cancer, treatment, side effects and symptom relief (Ranking of 74-87.9 out of 100). Women were least satisfied with the information they received about emotional reactions, counseling services, access to other women with ovarian cancer, self-help groups and complementary and alternative therapies (Scores of 27 to 47 out of 100).

Women perceived that access to information changed during the journey with ovarian cancer. Howell 2003⁽¹⁵⁾ conducted individual interviews with 18 Canadian women at the time of *ovarian cancer recurrence*. They indicated that it was more difficult to find information on treatment options at recurrence as compared to front line disease. These women felt they had to push the medical team for further information on treatment options. Some felt that their treatment options were limited because of their geographic location or lack of access to other subspecialists.

When women did not obtain the information they felt they required, they

were resourceful at getting information. Finn 2000⁽⁸⁾ interviewed 6 women from Hamilton, Canada with recurrent ovarian cancer. When these women did not get the information they wanted, they returned to the physician with a list of questions or with a family member who could advocate for their information needs. Zieband 2006⁽¹⁶⁾ conducted individual interviews with 43 women with ovarian cancer in the United Kingdom. These women indicated that they used second opinions as an opportunity to obtain more information about their disease and treatment options.

1.4. What information do physicians provide to patients?

To determine what information physicians actually provide to patients during the medical encounter, our group⁽¹⁰⁾ observed a number of physician-patient interactions where first line chemotherapy was discussed for women newly diagnosed with ovarian cancer. Physicians consistently provided patients with information concerning their disease status, the available management options (surgery followed by chemotherapy, chemotherapy alone, and supportive care only), chemotherapy and the treatment process. Potential side effects were described by one-third of physicians. Only one out of six physicians discussed the goals of treatment as prolonging survival time. In a questionnaire completed by the physicians after the observed medical encounter, physicians overestimated the information they said they would give a patient when compared with the information they actually gave the patient in the observed physician-patient interaction ($\kappa=0.52$ ⁽¹⁰⁾).

1.5. To what extent do women hear and/or understand the information presented to them in the medical encounter?

There is no study in the ovarian cancer literature that documents the extent to which women understand the information imparted to them in the medical encounter. Such work has been completed in other cancer disease sites. Whelan showed that patients with breast cancer do not always 'hear' or remember the information presented in the patient physician encounter⁽¹⁷⁾ This is an important finding because if the physician believes they explained the outcomes information but the patient does not understand the terms or the implications of this information, the patient may walk away from the encounter feeling dissatisfied or uninformed following the medical encounter and may act on misperceptions of the meaning of the information.

Using a qualitative study design with one on one interviews, Fitch in 2002⁽¹⁴⁾ interacted with 18 women at the *time of their diagnosis of ovarian cancer*. She found that these women felt that they were given little information or had little access to information at the time of diagnosis. She identified that this particular medical encounter occurred at a time when women were experiencing marked anxiety and depression, impaired social functioning, fatigue, pain, compromised sexuality and psychological distress. The women's physical and/or emotional distress may have impeded their ability to receive or process the information imparted by the physician.

Our group⁽¹⁸⁾ interviewed 21 Canadian women at the point of making a treatment decision for *first line chemotherapy*. We identified that women understood that the treatment had both potential survival and quality of life benefits. They could clearly articulate the potential risks. However, the

women spoke about being overwhelmed by the severity of their illness and grief over the cancer diagnosis. Jolicouer⁽¹²⁾ conducted 21 individual interviews with women with *recurrent ovarian cancer* from Ottawa, Canada. All of the women understood that their disease was not curable. However, her research group indentified that the longer the time from the decision making encounter to the interview, the greater the loss of detailed information retention among study participants. Howell 2003⁽¹⁵⁾ conducted 18 Canadian women with *recurrent ovarian cancer*. They found that the label of cancer was emotionally charged and the degree of unwellness may have prevented some women from taking in the details of the information presented. Thus, many factors related to the patient may influence her ability to receive and understand the information delivered during the medical encounter.

1.6. Physician Communication Style

Elit⁽¹³⁾ noticed in a series of interviews with 26 Canadian women with ovarian cancer at the time of *first recurrence*, that there were perceived differences among women about their physicians' style of information giving. The physician's styles varied on 5 dimensions: 1) physician's demeanor (quiet and business like, friendly, direct approach and admits uncertainty); 2) how the treatment options were presented to the patients (sequential - one option provided for each event verses simultaneous - where several options were given and the patient chooses one), 3) the depth of information provided (patient had to ask questions to illicit details versus information provided without prompting), 4) how the information was presented (verbal only, verbal with writing or other aids) and 5) whether or not a treatment recommendation was forthcoming.

An examination of the literature on the influence of physicians in the TDM process in other cancers shows that poor communication of disease status and treatment benefits and risks and options lead to poor outcomes such as patient dissatisfaction, lack of patient adherence to a treatment plan, poorer self reported health, poorer physician satisfaction and higher malpractice claims⁽¹⁹⁾. However, randomized trials of strategies to improve physician communication have not shown that the strategies tested improved communication scores⁽¹⁹⁾, lower patient distress⁽²⁰⁾, or lower patient or family anxiety⁽²¹⁾. There is no literature on the impact of physician style on information giving, deliberation or making the treatment decision in ovarian cancer. We are currently undertaking research on this topic.

1.7. Decision Aids

To enhance the information exchange in the medical encounter, there has been research assessing the usefulness of decision aids (DA). DAs are tools intended to help patient with decisions about their health care. They provide information on the disease, goals of treatment, treatment options, side effects and outcomes in a standardized way. DAs have been shown to improve knowledge without increasing anxiety⁽²²⁾. DAs can involve high technology interactive videos or be low tech, using flip charts with an audio aid. The Decision Board (DB) is one example of a DA. It is an enabling tool for information transfer from the physician to the patient; it is a supplement to the physician consultation but does not replace it. DBs were originally modeled on standard clinical practice with two-way interaction and so meet the ethical and legal principles of information consent and information transfer. These aids can be easily and cheaply modified as new relevant data are reported. They are used

to present information on potential risks and benefits in an unbiased fashion. DBs have been used in the context of ovarian cancer to elicit treatment preferences for first line chemotherapy⁽¹⁰⁾ and at the time of recurrent disease⁽²³⁾. The DB can provide an unbiased way of providing information (i.e., blinding the patient to the names of the drugs). They can also be used to objectively present survival information. The manner in which this information (i.e., percent survival at a point in time versus median survival) is presented can influence choice⁽¹⁰⁾. With some DBs, the patient can leave the patient-physician interaction with an 8"x11" printed version of the DB. The hand-out-version allows patients to reconstruct what the heard the doctor says in the patient-physician interaction. The DB has been shown to improve the retention of disease, treatment and outcome information.

To date the ovarian cancer literature explores the decision board uses in research settings for research purposes and not in regular clinical practice settings. Given the concerns voiced by patients that they want more information and given the research that shows physicians often do not provide the information they feel should be provided in the patient-physician interaction, the DB may be one adjunct to improve the information transfer component of TDM.

2. Deliberation

The deliberation stage of decision-making refers to the process of identifying values, expressing and discussing treatment preferences. How deliberation proceeds in part depends on the role patients and physicians assume in the information exchange stage. Both the patient's role and the physician's role is dynamic and may stay the same or change between as well as during each of the 3 stages.

2.1. What role do ovarian cancer patients want in deliberation?

Patient preference for participation in decision making can change depending on where the patient is in her journey with the disease. There is no literature that specifically addresses patients' preferred role in deliberation. There is literature about women's preferred role in the treatment decision making process in ovarian cancer which may provide insight into the role they may want in deliberation. Stewart's work⁽¹¹⁾ using questionnaires showed minimal fluctuation in preferences about who should make the treatment decision when women were first diagnosed, at the time of treatment and after treatment. In contrast, during individual interviews with women at first recurrence, both Howell⁽¹⁴⁾ and Elit⁽¹³⁾ identified that women felt their participation in decision making was more active. The authors did not elaborate on what "more active" means. In Howell's work, women felt they were more involved in decision making because of their experience with first line treatment and because they now had more knowledge about the disease. In Elit's work, patients with recurrent ovarian cancer sensed that the process of decision making was more straightforward. It is not clear if this means that at this point in time, they are more comfortable communicating within the cancer system or in articulating their preferences.

Deliberation can occur between the patient and physician alone or in the presence of family members or friends. Again there is no focused research on this issue and in particular as it pertains to deliberation. However, in some of the studies, both physicians and patients have indicated the desire to have a patient advocate in the room during the TDM process^(8,12,13).

Deliberation can take place directly with the physician or health care team or deliberation can occur outside the medical encounter. For example, the patient can work with an *internet tool* that is usually algorithm based. There are a few internet programs that allow women with ovarian cancer to work through a treatment decision in the comfort of the home on the computer. These tools are different than providing information. They ask patients specific questions about their disease (ie., stage, grade, histology). They provide treatment information and options. They help patients clarify their values and rate some treatment options as higher and lower in preference. The American Cancer Society website hosts a treatment decision tool from NexProfiler called the "treatment option tool". It asks specific demographic questions to provide detailed information for treatment options for patients with several types of cancer including ovarian cancer. The tool focuses on providing information and aiding the deliberation process by having the patient list all the positive things a woman and her doctor think concerning a treatment choice in one column and all the risks in a second column⁽²⁴⁾.

2.2. What values are important to women with ovarian cancer?

The concept of values is elusive. Some of the literature equates or freely interchanges "values" with "preferences". For the purpose of this chapter we define "values" as those things that are held in highest regard or most important for that individual. Values shape the decisions a person makes. They are the drivers or motivators or things for which we will sacrifice other things. Values answer the question "Why do I do what I do?" Values are acquired and so they can change.

As it pertains to decision making in women with ovarian cancer, values may influence the role the woman wants in the decision making process (ie., autonomy), and the treatment outcome that is most important to her (ie., living as long as possible, quality of life, time with family). There is no literature in ovarian cancer that identify which are the important values, how these values influence role or the treatment decision, or how values may change during the journey with the disease.

2.3. What are the treatment preferences in women with ovarian cancer?

We will use the phrase "*patient preferences*" to mean that the patient has explicitly identified a management strategy that reflects her values, beliefs and life goals, her understanding of her illness and her understanding of the potential risks and benefits associated with treatment. At the point of making a decision concerning *first line chemotherapy* for ovarian cancer, our group⁽¹⁰⁾ used a decision board to determine patient preference for treatment. We reviewed the DB with 37 women volunteers without cancer, 11 women with ovarian cancer who had completed chemotherapy and 12 women at the point of making the treatment decision for first line chemotherapy. The DB provided information about the disease, two chemotherapy treatment options, how they are administered and the frequency of expected side effects and survival information for each option. The names of the drugs were not used and side effects were presented by bar graphs. Women who had just completed surgery for advanced ovarian cancer who were at the point of TDM were given a copy of the board and had 24 hours to ponder the information. One-third of the women chose an older treatment

regimen with platinum cyclophosphamide and two-thirds chose platinum-taxol (the then novel treatment). No factors that we studied (ie, demographic characteristic, depression scores, quality of life score) predicted treatment choice. At this point in the disease journey, more patients valued survival more strongly than quality of life. The limitations of our study were that the treatment choice using the decision board may or may not have been the treatment ultimately delivered. How other factors in the patient-physician interaction affect the final choice of treatment actually taken still need to be determined.

Donovan 2002⁽²³⁾ probed the preference for management when a woman developed her first recurrence from ovarian cancer. One management option involved further chemotherapy with a less than 20% chance of response. Another option involved no active management of cancer but symptom management for the consequences of the cancer; for example, using anti-nausea medication for nausea and vomiting or removing fluid from the abdomen periodically for ascites. Donovan interviewed two groups of women. One group (n=81) included women who were currently receiving first *line treatment* for ovarian cancer. The second group (n=75) were women without a personal history of cancer. Women with ovarian cancer were five times more likely to choose salvage chemotherapy compared to non-cancer patients. They were more willing to tolerate the toxicity of chemotherapy even though they had non-curable disease. The one discriminating factor was that women who had a difficult time with first line chemotherapy (this involved 12.5% of the sample) were less likely to choose chemotherapy when the disease recurred. Most women switched to a decision for palliative care when they were told they had a survival of 3 months or less.

Twenty-five percent of ovarian cancer patients said they would never switch to palliative care even if survival was less than 1 week. Palliative care means no hope for survival; however, hope seemed to be derived from the fact that treatment was offered even if the treatment is futile. It appears that even in the context of decision aids where there is clear information on treatment options; patients may not use research evidence to make what most of us would term a "rationale" decision. This may mean that the patient does not believe the opinion of the health care team that they are dying or the estimate of time prior to their demise. It may mean that patients do not wish to think or acknowledge their demise (ie., give up hope). It may mean that patients do not want to use medical evidence to make their management decision. What this shows is the importance of patient preference. Decision making is not just about information exchange; but rather, it is about how this information takes on meaning for the patient.

2.4. Treatment recommendations: what role do they play in deliberation?

There are some physicians that provide patients with the information about treatment options and potential side effects and benefits but then stop and allow the patient to articulate their treatment choice. Zieband 2006⁽¹⁶⁾ conducted individual interviews with 43 women with ovarian cancer in the United Kingdom. These women found that being offered a treatment choice was not welcomed. When the reason for the choice was not provided (ie., not enough information to understand why a choice was even being discussed) or understood, the fact that they were given a treatment choice made them feel panicky and they tried to second guess what they thought the doctor really wanted them to do. Zieband found that if the woman felt

the doctor was unwilling to express his or her own preferences this led to confusion and concern about the right management. The general population is not used to being asked about their preferences and such a question can surprise or shock people. Zieband suggested that clinicians need to explain about clinical uncertainty and how individual values and preferences may relate to treatment decisions. David Mechanic⁽²⁵⁾ a well known medical sociologist, has observed that people want to feel part of their health care, but they don't want to be abandoned to making decisions all on their own. When a doctor says, "Here are your options" without offering expert help and judgement, this is often seen as a form of abandonment. Schwartz⁽²⁶⁾ is concerned that patients are overwhelmed when the opportunities are so numerous. Instead of being in control, patients lose the ability to cope. Being forced to choose in a life and death situation can become a grave burden to patients and if the choice turns out to be wrong it can lead to intense regret.

There are some physicians that provide women with only one treatment option or if other options are provided, the physician gives a strong treatment recommendation. When the physician provides a treatment recommendation, this reflects the physician's understanding of the information, his values and preferences. There is some ovarian cancer literature on the impact of providing treatment recommendations. In Jolicoeur's work⁽¹²⁾ with 21 women with *recurrent ovarian cancer*, during the individual interviews, half of the women sensed that the doctor knew how they would respond to treatment. The physician's treatment recommendation became the treatment they felt comfortable pursuing. In our work with women at the same point in the journey⁽¹³⁾, the 26 women who underwent a semi-structured interview indicated that they felt that

they made the treatment decision and /or influenced the timing of the chemotherapy. The women appeared to describe a process of coming to terms with living with cancer and accepting the treatment that their physician recommended. It appears that when there is a treatment recommendation made either spontaneously or upon the request of the patient or her advocate, this strongly influences the patient's future management.

2.5. What other factors aid in the deliberation phase?

In our study of women making a decision for *first line chemotherapy* for ovarian cancer⁽¹⁸⁾, 21 women felt that they gleaned support for their treatment decision by individual's who advocated for them (ie., spouse, family, friends), their faith and past experiences in the cancer system (ie., personal previous malignancy or journeying with a spouse or parent who had cancer). Hindrances to making a decision included people who were negative, the label of cancer and their employers. Our work suggests that both the treatment and time of treatments vary and are influenced by factors external to the clinical context such as social networks and life events. Hence it is important for oncologists to promote an environment where other factors have time to interact with the information exchanged.

The current literature is lacking on how the deliberation phase affects patients (ie., anxiety, depression, satisfaction with the decision), how long this process should last, and to what extent and how other factors (time alone, time talking with friends and family, discussions with other health care providers) influence the deliberation process. There are unanswered questions concerning strategies that can help patients make their implicit values explicit and how this may or may not impact on treatment

preferences, how physician's values and preferences can influence this deliberation process and patient satisfaction with the decision or compliance with treatment.

3. Making the Treatment Decision

The culmination of the process of information exchange and deliberation is making the decision. It is the actual verbalizing of a treatment choice and moving forward with a treatment plan. In this section we are going to reviews 1) What do treatment options/choices mean to the patient? 2) Is no treatment, an option? 3) What role patients want, 4) Making the treatment decision, and 5) Factors involved in abdicating the treatment decision to the medical team.

3.1, *The range of options discussed*

One would think that making a treatment decision implies that the patient has management options. In our work using individual interviews with 21 women at the time of *first line chemotherapy* for ovarian cancer⁽¹⁸⁾, we noted that most women did not perceive that they had a treatment choice yet they felt that they made the decision. Few women perceived that they were given a choice between 1 versus 2 drugs which suggests that physicians may have only offered one option as endorsed by the practice guidelines (i.e., a 2 drug regimen). As well, patients may not have recognized "no treatment" as an option. In other words, the patients' decision style was a process of coming to terms with the disease and the recommended treatment. Interestingly, both our respondents and those of Jolicoeur⁽¹²⁾ felt the physician knew which treatment was "right" for them and were confident in their cancer physician. In Jolicoeurs individual interviews with 21 women with *recurrent ovarian cancer*, 13 perceived there was a decision to make

and 5 felt they had received treatment options. It is not clear if the other 8 women perceived that the treatment decision was agreeing or disagreeing with the treatment recommendation. It appears that making a treatment choice for patients is not about recognizing options or choosing between options, rather it means coming to terms with a treatment recommendation.

3.2. *Women's perceptions about no treatment as an option*

During the journey with ovarian cancer, one of the options is always – not to intervene, or as some phrase it, symptom management (alias palliative care). For example, the symptom of pain is managed with analgesics, shortness of breath is management by taking fluid off the lung but this is done within the context of no cancer fighting treatment (like chemotherapy). As described above, in our study with 26 women at the point of first line chemotherapy for ovarian cancer, "no treatment" did not appear to be recognized as an option. At the point of disease recurrence, when there is only a 20% or 1 in 5 chance that any chemotherapy will cause the cancer to shrink, the concept of "do nothing is not an option" is a theme that surfaces again. In Jolicoeur's study⁽¹²⁾ of 21 women with recurrent ovarian cancer, a third of those interviewed felt they received treatment options - with no treatment as one of the options. These women felt that to do nothing was not a viable option. In Zieban's individual interviews with 46 women with recurrent disease in the United Kingdom⁽¹⁶⁾, "no treatment" was not seen as an option if you wanted to survive. It appears from Donovan's work in women with first line chemotherapy that the closer the certainty of death⁽²³⁾, the more likely women will shift to a symptom management decision; however, 25% of women with ovarian

cancer say they will never shift. Whether this choice is stable outside of the research hypothetical setting compared to reality, has yet to be determined.

3.3. How the treatment decision is made

The role the patients plays in the decision making process is dynamic; it may change between the 3 stages of DM or even during one of the stage. Not all women with ovarian cancer want the same role in decision making. Stewart⁽¹¹⁾ asked 105 women from Toronto Canada, at any point in the journey with ovarian cancer: Who should make the treatment decision? Approximately 20% wanted the doctor to make the decision, 15% wanted to make the decision themselves and 60% wanted to share the decision with the doctor. Jolicoeur⁽¹²⁾ in individual interviews with 21 women with *recurrent disease* found that they felt they played the decision making role they preferred. Elit⁽¹³⁾ showed in 21 women at the point of making a treatment decision for *first line chemotherapy* for ovarian cancer, women indicated that they wanted to be involved in the TDM process. It was not clear whether “involvement” meant being informed, assessing their values and preferences and/or making the decision. Sutherland suggested that some women want information but they do not want the responsibility for making a treatment decision. The literature suggests that in patients with other types of cancer, they are more likely to want the physician to make the treatment decision⁽²⁷⁾ especially if they are older⁽²⁸⁻³⁰⁾, married⁽²⁸⁾, women and less educated^(29,31).

3.4. Factors that appear to influence the treatment decision

A repeated message in all of the individual interviews was that making a treatment decision was coming to terms

with the treatment recommended by the physician. Fitch⁽⁶⁾ conducted individual interviews with 18 women. They articulated minimal involvement in initial treatment decision making and the treatment decision was made by physician. Patients went along with the decision because they wanted help for the discomfort they were experiencing or because they felt they did not know enough about ovarian cancer or its treatment to make a contribution to the decision. As described in section 2.4 a few women indicated that they actively chose to let the medical team make the treatment decision for them, or they do not recognize being actively involved in the decision and just went along with the treatment recommendation proposed by the medical team.

3.5. Factors involved in abdicating the decision to the medical team.

In part, the woman’s lack of involvement in making the treatment decision is undergirded by an urgency to make the decision. In Fitch’s 2003 work⁽⁶⁾, the 18 Canadian women with ovarian cancer who noted that the initial discussion of the disease evoked shock and fear, usually were quite ill at the time of diagnosis. They felt incapable of participating in the decision making process because of lack of knowledge. They felt rushed through the decision making. Our group⁽¹⁸⁾ interviewed 21 Canadian women when *initially diagnosed* with ovarian cancer. We identified that women felt overwhelmed by the severity of their illness and they felt they needed to make a treatment decision right away in order for the treatment to reverse their dire symptoms.

Summary

Ovarian cancer is a journey from diagnosis and adjuvant therapy through

recurrence and ultimately the time prior to death (palliative period). There are decisions that need to be made concerning management of the disease all along this continuum. The decision making process includes information exchange, deliberation and making the decision. There is a breadth of literature available on the stage of information exchange; however, there has been minimal exploration on the stage of deliberation. Most of the research comes from qualitative and survey studies. Most of the studies have been done in the Canadian context, with little work available in ovarian cancer from other jurisdictions. Thus we do not know if cultural differences affect the TDM process in this population. Interest in the ovarian cancer patient's decision making appears to come from the supportive care discipline; perspectives may be varied if physicians (who are one of the players in TDM) were more actively involved in this research. The research that is available appears to answer specific questions without any origin or connect to a model of decision making. In contrast, the current research has not yet matured into a model of decision making. The current research does not appear to look at decision making over the ovarian cancer journey. Thus how preferences change over time, how the patient or physician desired role in each stage of the three stages stays the same or changes has not been explored.

Conclusion

Making a decision concerning treatment of ovarian cancer across the woman's journey with the disease is important. There is a growing literature focused on information exchange, one of the three stages of decision making. There is minimal research on the stage of deliberation.

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