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Decision Support for a Woman Considering Continuing Extended Endocrine Therapy for Breast Cancer: A Case Study

by Carrie M. Liska and Dawn Stacey

ABSTRACT

This case study evaluated decision coaching with a breast cancer survivor considering continuing extended endocrine therapy from eight years to 10 years. The survivor, aged 58 years and who completed surgery and chemotherapy eight years ago, was concerned about side effects of endocrine therapy. Decision coaching based on the Ottawa Decision Support Framework involved an oncology nurse using the Ottawa Personal Decision Guide. Compared to baseline (2 out of 4), decisional comfort improved (3 out of 4) post decision coaching. The survivor felt more certain, but wanted further advice from her oncologist. She was leaning toward discontinuing endocrine therapy given she valued quality of life over a small risk of recurrence. Audio-recording analysis using the Decision Support Analysis Tool revealed high decision coaching quality (10/10). Breast cancer survivors facing preference-sensitive decisions about extended endocrine therapy could be supported with decision coaching by oncology nurses to ensure informed values-based decisions.

BACKGROUND

Breast cancer mortality has dropped in recent years due to improvements in early detection and treatment (Buijs, de Vries, Mourits, & Willemse, 2008). Treatment with adjuvant endocrine therapy is proven to be highly effective for the treatment of hormone receptor positive breast cancer and is prescribed for five years, as the standard of care for nearly all women (Burnstein et al., 2014; Davies et al., 2013). More recently, however, women have been offered extended adjuvant endocrine therapy for a duration of 10 years based on findings from multinational randomized studies (Burnstein et al., 2014; Davies, et al., 2013; Goss et al., 2008). Consequently,

the American Society of Clinical Oncology has updated the Clinical Practice Guideline recommending 10 years of endocrine therapy where the risk of recurrence remains substantial and the patient's age and current health warrant the additional treatment (Burnstein et al., 2014).

Concurrently, there are more side effects with longer-term endocrine therapy and none of these studies examined quality-of-life outcomes or potential harms such as endometrial cancer, hot flashes, menopausal symptoms, deep vein thrombosis or pulmonary embolism, ischemic heart disease, osteopenia/osteoporosis, and sexuality issues (Burnstein et al., 2014; Davies et al., 2013; Faguy, 2013). In fact, longer trial follow-up is required to assess the full benefits and harms throughout the second decade after endocrine therapy (Davies et al., 2013).

Given the gap in evidence about longer-term side effects, clinicians are encouraged to individually assess and gauge health-related quality of life for patients taking extended endocrine therapy (Burnstein et al., 2014). Many cancer survivors consider their quality of life equally as important as their length of life (Faguy, 2013). Current practice guidelines omit shared decision making, however, patients experience better psychological adjustment when they receive appropriate information, are given choices, and are involved in the decision-making process (Khatcheressian et al., 2013; Sussman et al., 2012). Therefore, women should be included in discussions about extended endocrine therapy to incorporate the impact of treatment on quality of life into the decision-making process (Harmer, 2008).

Oncology nurses have opportunities to support patients making difficult decisions by providing decision coaching and using patient decision aids to enhance quality patient-centred oncology care (Saarimaki & Stacey, 2013). Decision coaches recognize patients experiencing decisional conflict. They can provide non-directive guidance in the process of this decision making by assessing factors influencing patient's decisional conflict, verifying patients' understanding of their options, and helping patients clarify what is most important to them (Stacey et al., 2008b). In fact, patients think that nurses should also communicate their informed preferences to the physicians (Joseph-Williams et al., 2014). As a result, oncology nurses are particularly well suited to support patients who are making decisions about cancer treatments.

The aim of this case study was to evaluate the provision of an oncology nurse's decision coaching for a breast cancer survivor making a decision about continuing extended endocrine therapy.

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METHODS

Study Design

A prospective case study was guided by the Ottawa Decision Support Framework. Case studies investigate descriptive or explanatory questions and aim to produce a first-hand understanding of people and events (Yin, 2004). A case study method was chosen because in comparison with other methods, it allows for more in-depth examination of a case within the context of real life experiences. The University of Ottawa Research Ethics Board approved the study as an assignment within a graduate nursing course (File # NSG6133/6533).

Framework

The Ottawa Decision Support Framework (ODSF) has been empirically tested and utilized to (a) identify patient's decisional needs, (b) guide the development of decision support interventions such as decision aids and decision coaching, and (c) evaluate the quality of decisions made (O'Connor, Jacobson, & Stacey, 2002; Stacey et al., 2009). According to this framework, when decision support is provided and tailored to unresolved decisional needs, higher decision quality is achieved. The framework defines decision quality as being informed and based on individual values.

Participant

A client was conveniently chosen for participation in this study because she was experiencing difficulty deciding about whether or not to continue extended endocrine therapy. The client had recently completed eight years of endocrine therapy. Due to side effects from the medication, she told the oncology nurse that she felt unsure about whether or not to continue for another two years to reach the recommended ten years of therapy. As well, she was able to read and communicate in English and sign the consent for study participation.

Procedures

An oncology nurse graduate student (CL) was trained as a decision coach by successfully completing the online Ottawa Decision Support Tutorial and attending a graduate level university course titled Decision Making in Clinical Practice. The client was screened to confirm decisional conflict on June 11th, 2015 using the SURE Test (Legare, et al., 2010). In preparation for the decision support session, the client was asked to consider her options about endocrine therapy and the decision coach, sought to find a relevant patient decision aid and/or other information on the options.

After signing the consent form, decision coaching was provided on June 12 by CL using the Ottawa Personal Decision Guide (OPDG). The session was audio-taped using the smart phone application voice memo. At the end of the decision support session, the client completed the SURE Test to re-screen for decisional conflict and confirm outstanding decision needs.

Decision Coaching Intervention

Patient decision aids are interventions to help patients consider treatment options and their outcomes, clarify their personal values, and proceed through the steps of deliberation and communication with a health care provider (Stacey et al., 2014). There were no patient decision aids specific to the decision about extended endocrine therapy for breast cancer

(Patient Decision Aids Research Group, 2016). The Ottawa Personal Decision Guide (OPDG), based on the Ottawa Decision Support Framework, is a generic decision aid that assists practitioners and/or patients structure their decisional needs assessment, support in process of decision making, and re-evaluate decisional needs (Feenstra et al., 2015). The OPDG was selected to be appropriate for guiding the decision coaching in this case study (see Figure 1).

The OPDG has been evaluated in numerous studies with nurses, psychologists, and health promoters providing decision coaching (Stacey et al., 2008b). When used in practice, health professionals have enhanced skills and are more likely to assess patients' information needs, discuss values associated with their options, and discuss support needs related to others involved in the decision. A systematic review of 10 randomized controlled trials showed that decision coaching improves patients' knowledge and has had no harmful effect on other outcomes such as satisfaction, values-choice agreement, participation, and cost (Stacey et al., 2012). Utilizing the OPDG, in conjunction with coaching, has been shown to clarify values and coach patients in the process of thinking about their options (Arimori, 2006; Feenstra, 2015; O'Connor, Legare, & Stacey, 2003).

Instruments

The SURE Test is a four-item screening instrument that identifies patients with decisional conflict (Legare et al., 2010). Positive responses to each of the scores are given a point and combined total scores less than four indicate the patient is experiencing decisional conflict. The SURE test is a validated tool which has demonstrated adequate internal consistency and is negatively correlated with the original decisional conflict scale—as SURE test results increase, decisional conflict decreases (Ferron Parayre et al., 2013).

The Brief Decision Support Analysis Tool (DSAT-10) evaluates practitioners' use of decision support provided to patients facing value-sensitive health decisions (Butow et al., 2009; Stacey, Taljaard, Drake, & O'Connor, 2008a). The DSAT-10 has adequate inter-rater reliability and a kappa coefficient of 0.55 over all items, with greater agreement demonstrated in nurses trained in providing decision support. Both the SURE test and the DSAT-10 are based on the Ottawa Decision Support Framework.

Data Analysis of the Case Study

Change in the SURE test results were analyzed descriptively by CL. The audio transcript of the decision coaching was analyzed using content analysis based on the DSAT-10 (Stacey, Taljaard, Drake, & O'Connor, 2008a). This involved listening to the recording three times to determine items on the tool that were met and documenting quotes to support the ratings.

RESULTS

The cancer survivor is a 58-year-old woman who was initially diagnosed in 2006 at the age of 49 with clinically locally advanced left breast cancer (T3 No Mo multifocal multicentric estrogen negative, progesterone positive, HER2 negative). As per protocol, she underwent eight cycles of neo-adjuvant chemotherapy. Due to atypical cells detected in the contralateral breast at the time of the initial diagnosis,

Ottawa Personal Decision Guide For People Making Health or Social Decisions

1 Clarify your decision.

What decision do you face? Whether to continue endocrine therapy for a ten year total duration or do nothing - no further medication

What are your reasons for making this decision? The side effects are almost intolerable vs medical advice to continue

When do you need to make a choice? Would like to make a choice by the next oncology appointment, July 2015

How far along are you with making a choice? ☐ Not thought about it ☒ Close to choosing
☐ Thinking about it ☐ Made a choice

2 Explore your decision.

Knowledge

List the options and benefits and risks you know.

Values

Rate each benefit and risk using stars (★) to show how much each one matters to you.

Certainty

Choose the option with the benefits that matter most to you. Avoid the options with the risks that matter most to you.

	Reasons to Choose this Option Benefits / Advantages / Pros	How much it matters to you: 0★ not at all 5★ a great deal	Reasons to Avoid this Option Risks / Disadvantages / Cons	How much it matters to you: 0★ not at all 5★ a great deal
Option #1 To continue with an aromatase inhibitor endocrine therapy.	Potential reduction risk recurrence	★★	Decrease bone density	★★★★
			Arthralgia	★★
			No energy for work or social	★★★★
Option #2 To do nothing - to not take any further medication.	Minimal side effects	★★★	The unknown of not taking med	★
	Less reminder each day of br.ca.	★★★	If reoccured, then self-blame	★
Option #3				

Which option do you prefer? ☐ Option #1 ☒ Option #2 ☐ Option #3 ☐ Unsure

Support

Who else is involved?	Medical Oncologist	Husband
Which option do they prefer?	Continue for total duration of 10 yrs	It's her decision
Is this person pressuring you?	☒ Yes ☐ No	☐ Yes ☐ No ☐ Yes ☐ No
How can they support you?	By hearing about the side effects	He's been very supportive throughout
What role do you prefer in making the choice?	☒ Share the decision with... ☐ Decide myself after hearing views of... ☐ Someone else decides...	Still have to have a conversation about clarifying the evidence and sharing how the side effects are tremendous. But ultimately the clients decision & will share her personal values

Ottawa Personal Decision Guide © 2015 O'Connor, Stacey, Jacobsen. Ottawa Hospital Research Institute & University of Ottawa, Canada. Page 1 of 2

Figure 1: Client's responses on the Ottawa Personal Decision Guide

the client elected to undergo bilateral mastectomies following the completion of chemotherapy. On the left side, there was no evidence of residual disease (pathological complete response) and there was no evidence of disease on the contralateral side. Thereafter, she underwent adjuvant radiation therapy to the left chest wall and supraclavicular node region. Given that the tumour was progesterone receptor positive, she commenced endocrine therapy with a GNRH analogue and an aromatase inhibitor. In 2008, she underwent an abdominal hysterectomy and bilateral salpingo-oophorectomy, stopped the GNRH analogue, and continued on the aromatase inhibitor.

This individual received an aromatase inhibitor for a total duration of eight years. She described side effects due to endocrine therapy affecting her health-related quality of life to include osteopenia, hot flushes, mood swings, arthralgia, increased cholesterol, and fatigue. These side effects profoundly affected her personal and work life. Her social history includes being married, with no children, and employed full-time.

The baseline SURE Test score was 2 out of 4 revealing decisional conflict with decisional needs in the areas of feeling uncertain and unsupported (see Table 1). Utilizing the OPDG, the client explicitly reported having two options: (a) to continue extended endocrine therapy for two more years to achieve

a ten-year total duration or (b) to stop taking further endocrine therapy. The client articulated being “70 percent” in her decision making stage and leaning toward stopping endocrine therapy (see Figure 1). She reported wanting to make this decision before her next visit with the medical oncologist in July, 2015. The client reported having two individuals involved in the decision: (a) her husband who felt the decision was hers to make, and (b) her medical oncologist who the client felt was pressuring her to continue the medication for a total duration of ten years. The woman felt the decision was ultimately hers to make.

When the decision coach and the client used the OPDG to explicitly explore knowledge of the two options, her values toward outcomes of options and certainty about her preferred options, the client preferred stopping endocrine therapy. Her reasons to stop endocrine therapy were to avoid the medication side-effects that: (a) affected her lifestyle and subsequently impacted on her work and personal life, and (b) decreased her bone density (see Figure 1). She rated both of these reasons with four out of five stars indicating very important and outweighing the potential benefit of reducing breast cancer recurrence, which she indicated as less important with two stars. Another reason for stopping endocrine therapy was to not be reminded of the cancer when taking the medication each day (three stars of importance). The unknowns about not taking the medication and potential self-blame were rated as less important with one star. Overall, the client reported that the small reduction in risk of breast cancer recurrence was less important to her than the medication side effects that affected her quality of life. For example, she said, “*I know it sounds kind of weird... you want to extend life as much as you can, but I think, you know, having the chance now that it might come back has dropped enough that I feel that if I can't have the quality of life, then why am I doing this*” and “*it's about living life to the fullest and that is what I value most*”.

At the end of the decision coaching session, the client reported that what she valued most was delineated and she stated, “*I am now much more resolved with doing nothing (not taking further medication)... I think just closing off and having that final conversation (with medical oncologist).*”

Following decision coaching, the SURE Test showed improvement in the area of certainty but she continued to have an outstanding need for support/advice (see Table 1). To address this remaining need, the client and decision coach reviewed the next step of discussing her decision with her medical oncologist at her next visit scheduled in July, 2015.

More specifically, she planned to (a) ask her medical oncologist to clarify the evidence around decreasing recurrence risk by continuing her specific endocrine therapy beyond five years and (b) to clearly inform her oncologist about the number of side effects affecting her health-related quality of life and interfering with her work and personal life. The client verbally conveyed that she felt empowered and confident with the planned intervention to meet her outstanding need.

The decision coaching session was 44 minutes long. Analysis by CL of the audio-taped session using the DSAT-10 indicated high quality decision support with a score of 10 out of 10 (see Table 2). As observed through field notes, the client appreciated the decision support, indicated the process was shared, and communicated a plan to address her outstanding need for advice from her medical oncologist.

DISCUSSION

In this case study, we demonstrated that providing decision coaching guided by the Ottawa Personal Decision Guide was helpful to support a woman considering whether or not to continue extended hormone therapy over the eight- to 10-year period. Compared to baseline, this client had decreased decisional conflict and identified her remaining decision-making needs indicating the desire for more specific advice from the medical oncologist. A strategy was planned to address the outstanding need in her next visit with the medical oncologist. These findings are consistent with studies evaluating patient decision aids and the Ottawa Decision Support Framework (Arimori, 2006; Stacey et al., 2014). Analysis of the interview revealed high-quality decision coaching, which was also confirmed through the client’s comments.

Reflections on the Process of Decision Coaching in This Case Study

The decision coaching process provided by a trained oncology nurse occurred as a natural ease of discussion (Table 2). Coaching was facilitated using open-ended questions based on the OPDG, with little interjection, and the client responded with a greater amount of communication during this exchange. The coach also used active listening by reflecting back to ensure her understanding of the clients’ comments. Open-ended questions and active listening are communication skills that result in two-way exchange and patients are more likely to be involved in the decision making process (Guimond et al., 2003).

Table 1: Client’s Baseline SURE Test Results			
SURE Domain	SURE Item	Baseline	Post Decision Support
S: Certainty	Do you feel SURE about the best choice for you?	No	Yes
U: Knowledge	Do you know the benefits and risks of each option?	Yes	Yes
R: Values	Are you clear about which benefits and risks matter most to you?	Yes	Yes
E: Encouragement	Do you have enough support and advice to make a choice?	No	No
Total Score		2 out of 4	3 out of 4
SURE Test © O’Connor & Legare, 2008 (Yes = 1 point; No =0 points)			

Table 2: Evidence of quality decision coaching using the Decision Support Analysis Tool			
Assessment Criteria	Hear acknowledge or assess	Intervened	Evidence from the decision coach
Identify uncertainty with decision	X (1 point)		"You indicated on the SURE test that you have decision conflict, can you tell me about the decision that you're facing?"
Timing for the decision	X (1 point)		"When do you feel you need to make this choice by?"
Stage of decision making	X (1 point)		"How far along do you feel you are in making your decision?"
Options AND Potential benefits of options AND Potential harms of options	X X X (if all checked 1 point)	N/A N/A N/A (if all checked 1 point)	"Can you tell me the options you feel you have and I'll write down on the document the options you feel you have." For Option one: "What benefits do you feel you would have by being on the Aromatase Inhibitor?" "And being on the Aromatase Inhibitor, what harm do you feel in that?" For Option two: "So when we look at your second option, tell me what your second option is?" "What benefits do you feel are there?" "Those are the benefits, what would be the reasons to avoid, or the risk, or the disadvantages of not doing anything." "Well, it is clear that you are aware of what the more recent research has demonstrated around the benefit but the quality of life issues."
Discuss importance of benefits AND Discuss importance of harms	X X (if all checked 2 points)		"Looking at these options, can you think about the benefits that are truly most important to you?" "If we look at the reasons to avoid an Aromatase Inhibitor, how much would that mean to you?" "If you think about the benefits you have mentioned about not taking the medication, how much does this matter to you?" "How much does it matter to you to avoid not taking medications, such as the unknown?" "How important do you rate the overall benefits of taking or not taking the Aromatase Inhibitor?" "What I'm hearing is that the quality of life issues that come with not taking the medication."
Discuss preferred role in decision making and other involved	X X (if all checked 1 point)	X X (if all checked 1 point)	"Is there anyone else involved in the decision?" "Are you feeling any pressure from anyone to choose a specific option?" "And your husband would prefer...?" "How do you think they could support you – looking at your husband perhaps?" "Can you think of how your oncologist could support you?" "So if we recap and go back, looking what you really value, do you know what's most important to you?"
Near end of the encounter, summarize the next steps to address patient's decision making needs	X (1 point)		"Do you have enough advice and the support you need to make your final decision?" "Do you feel sure about what your best choice is after working through this?" "So I'm hearing that ultimately it's your decision to make but you'll hear from your oncologist the pros and cons, including percentages." "What else do you feel you need to make a choice?" "Do you have any questions that you would like to ask to clarify anything?" "Do you feel comfortable sharing this preferred option with your oncologist at the visit?" "So bringing these options to your oncologist in July is really the next step?"
Total Score	10/10		

In this case study, the client clearly articulated evidence-based knowledge about extended endocrine therapy. Subsequently, with prompting by the decision coach, the client's personal values and preferences emerged through the weighing of benefits and harms, as well as when she considered the influence of others involved in the decision. Key elements of the decision coaching role include verifying understanding of the options, clarifying values for outcomes of the options, building skills in deliberation, and communicating with others involved in the decision (Stacey et al., 2012). Both the client and coach perceived this coaching approach to

be the most successful part of the decision support process. Although the client articulated that she preferred to make the decision, her medical oncologist's opinion was still important. This is consistent with the intentions of these interventions (e.g., coaching, OPDG) that were designed as adjuncts to counselling and not to replace counselling with the physician (Stacey et al., 2014). Finally, the OPDG provided a logical approach to planning the next steps for the client to address her outstanding needs (Stacey et al., 2008b). The decision support process may have been improved by the coach offering a follow-up discussion, as needed.

Given the prevalence of treatment with extended endocrine therapy for women with breast cancer, findings from this case study could be transferable to other women experiencing uncertainty about continuing therapy. In applying this approach, a decision coach should be cognizant that not all women considering endocrine therapy will possess as high a degree of breast cancer knowledge as the client in this case study. Therefore, the coach may need to intervene by using another element of coaching defined as providing evidence-based information on options, benefits, and harms (Stacey et al., 2012). Alternatively, a patient decision aid could be used as an effective intervention for providing information on options, benefits, and harms (Stacey et al., 2014). Interestingly, there was no patient decision aid specific to this topic in the international inventory (Ottawa Hospital Research Institute A to Z Inventory). The OPDG was useful in this case study to explore the client's current knowledge of benefits and harms of options and identified any gaps in her knowledge.

Reflection on the Relevance of Decision Support in Clinical Practice

Previously, women receiving extended endocrine therapy would be followed by an oncologist for up to 10 years (Rushton et al., 2015). Currently, most breast cancer survivors are transferred to primary care professionals for providing safe follow-up care or are followed through institution-based oncology nurse-led care (Grunfeld et al., 2006; Grant, De Rossi, & Sussman, 2015; Rushton et al., 2015). Nurses and primary care providers are positioned to engage breast cancer survivors in making some decisions (e.g., return to work) or at a minimum, coach them to prepare for discussing other decisions with their oncologist (e.g., length of endocrine therapy).

Challenges and barriers may interfere with patient engagement in shared decision making. Facilitators to implement shared decision making include using interventions targeting patients, such as patient decision aids, and others targeting healthcare professionals such as training (Legare et al., 2014). As evidenced in this case study, the oncology nurse was trained

in decision making and well-positioned to meet the individual needs of a breast cancer survivor contemplating continuing extended endocrine therapy. In this decision, there needs to be an acceptable balance between how long a patient lives and how well they live (Erren et al., 2012). When cancer survivors believe they have some personal control over decision making, they generally achieve a higher quality of life (Morgan, 2009). At a minimum, women should be assessed to determine their individual information needs and their health-related quality of life (Burstein et al., 2014; Feldman-Stewart et al., 2013). As well, they can be engaged in discussions about weighing the benefits and harms when considering the decision to take extended adjuvant endocrine therapy.

CONCLUSION

Breast cancer survivors experience many side effects from endocrine therapy that can interfere with their quality of life. Decisions about the length of endocrine therapy must weigh the benefits of survival against a negative impact on quality of life. This case study evaluated the provision of an oncology nurse's decision coaching for a breast cancer survivor making a decision about continuing extended endocrine therapy beyond eight years or stopping treatment. Following decision coaching using the OPDG, the breast cancer survivor had decreased decisional conflict and identified a plan to address her remaining decisional need. The client expressed feeling empowered and prepared to address her outstanding decision need at the next medical oncology visit through conveying her preference. Women making a decision about extended endocrine therapy can be active participants in a shared decision making process to achieve informed decisions based on their personal values. As treatment for breast cancer continues to advance, oncology nurses are well-positioned to provide decision support to ensure patients' decisions are based on their individual needs and informed preferences.

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