Promoting consultation recording practice in oncology: identification of critical implementation factors and determination of patient benefit

Thomas F. Hack^{1,2,8}*, J. Dean Ruether^{3,4}, Lorna M. Weir^{5,6}, Debjani Grenier^{2,7} and Lesley F. Degner¹

*Correspondence to: Room CR3018, Asper Clinical Research Institute, St. Boniface Research Centre, 369 Taché Avenue, Winnipeg, MB, Canada R2H 2A6. E-mail: thack@sbrc.ca

Abstract

Objective: The objectives of this implementation study were to (i) address the evidentiary, contextual, and facilitative mechanisms that serve to retard or promote the transfer and uptake of consultation recording use in oncology practice and (ii) follow patients during the first few days following receipt of the consultation recording to document, from the patient's perspective, the benefits realized from listening to the recording.

Methods: Nine medical and nine radiation oncologists from cancer centers in three Canadian cities (Calgary, Vancouver, and Winnipeg) recorded their primary consultations for 228 patients newly diagnosed with breast (n = 174) or prostate cancer (n = 54). The Digital Recording Use Semi-Structured Interview was conducted at 2 days and 1 week postconsultation. Each oncologist was provided a feedback letter summarizing the consultation recording benefits reported by their patients.

Results: Sixty-nine percent of patients listened to at least a portion of the recording within the first week following the consultation. Consultation recording favorableness ratings were high: 93.6% rated the intervention between 75 and 100 on a 100-point scale. Four main areas of benefit were reported: (i) anxiety reduction; (ii) enhanced retention of information; (iii) better informed decision making; and (iv) improved communication with family members. Eight fundamental components of successful implementation of consultation recording practice were identified.

Conclusions: Further randomized trials are recommended, using standardized measures of the patient-reported benefit outcomes reported herein, to strengthen the evidence base for consultation recording use in oncology practice.

Copyright © 2012 John Wiley & Sons, Ltd.

Received: 2 December 2011 Revised: 15 June 2012 Accepted: 22 June 2012

Introduction

The weeks following a diagnosis of cancer can be emotionally and cognitively taxing for patients as they come to terms with their diagnosis and start treatment. Communicating to sufficiently informed cancer patients is difficult [1-3], leaving a significant proportion of patients feeling overwhelmed despite having accessed multiple sources of information [4]. Information recall is particularly compromised for older patients and those with poor prognoses [5]. The primary oncology consultation is an important, essential meeting during which cancer patients begin their interaction with an oncologist and have their treatment options explained. The need for interventions to address the information needs of cancer patients is highlighted in a recent systematic review that reported that those patients whose information needs have been met, those who experience fewer information barriers, and those who are more satisfied with communication are significantly less anxious and less depressed [6].

One promising intervention for addressing the unmet information needs and concerns of newly diagnosed

cancer patients is that of providing them with a recording of their primary oncology consultation [7–21]. Reviews of the empirical evidence support the conclusion that audiotaped recordings of oncology consultations provide valuable benefits to cancer patients [22-26]. Consultation recordings allow for memories to be refreshed, for the learning of information not recalled from the initial consultation, for a clearer understanding of one's cancer treatment [10,15,16], for greater confidence that critical aspects of the disease and treatment have been discussed [11–13], and for greater information recall in comparison to nontape controls [7,9,18,20,27]. Consultation recordings provide patients with a means to initiate treatment discussions with family members [8,15-18] and help patients assume a significantly more active role in subsequent consultations [10] and in treatment decision making [28]. Consultation recordings have been shown to be particularly beneficial in reducing anxiety in cancer patients with low socioeconomic status [20]. A recent review concluded that consultation audiotapes significantly enhance recall in comparison to standard, orally delivered information, and that these benefits in recall are not realized using audiotapes

¹Faculty of Nursing, University of Manitoba, Winnipeg, MB, Canada

²CancerCare Manitoba, Winnipeg, MB, Canada

³Tom Baker Cancer Centre, Calgary, AB, Canada

⁴Faculty of Medicine, University of Calgary, AB, Canada

⁵British Columbia Cancer Agency, Vancouver, BC, Canada

⁶Faculty of Medicine, University of British Columbia, BC, Canada

⁷Department of Internal Medicine, University of Manitoba, Winnipeg, MB, Canada

⁸Asper Clinical Research Institute, St. Boniface Research Centre, Winnipeg, MB, Canada

of general, standardized information [26]. Patients also prefer consultation recordings over standardized recordings [14] and general summary letters [21]. Consultation recordings are well received by the majority of cancer patients; patient satisfaction with this intervention is high [8,9,12,13,18,19,21].

Despite the empirical evidence supporting the provision of consultation recordings, the uptake of this intervention into oncology practice has not been widespread. Barriers to successful uptake include lack of knowledge of benefit evidence, low perceived value, high cost, legal costs, time constraints, and technological and delivery mode challenges. Although these barriers have been discussed previously [29], to date, no consultation recording study has used a theory-guided approach to examine these barriers. The primary purpose of this implementation study was to address the contextual and facilitative mechanisms that retard or promote the implementation of consultation recordings in oncology practice, with an aim to increasing consultation use among oncology staff.

Implementation research is the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice and, hence, to improve the quality and effectiveness of health services and care [30]. This implementation study was guided theoretically by the Promoting Action on Research Implementation in Health Services (PARIHS) framework (Figure 1) [31–35], which posits that knowledge uptake can be explained as a function of the dynamic relationships among evidence (research, clinical experience, and patient preferences), context (culture, leadership, and measurement), and facilitation (characteristics, role, and style). The most successful implementation occurs when evidence is robust, the context is receptive to change, and where the implementation effort is appropriately tailored to the given context under study [36]. In accordance with a recent review that highlighted the importance of using the PARIHS framework in a prospective manner [37],

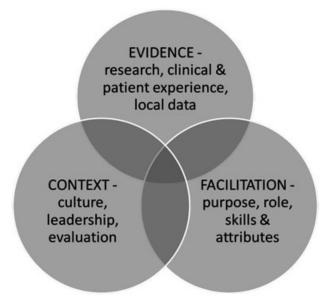


Figure 1. Promoting Action on Research Implementation in Health Services framework: interrelationship of evidence, context, and facilitation

the components of this framework were systematically examined throughout this implementation study.

Although previous consultation recording studies have used standardized, validated measures to identify the patient benefits of information recall, anxiety reduction, and increased satisfaction with communication, no study has systematically assessed benefits to patients captured in their own words. Use of current measures of patient benefit may be based on biased presumptions of patient benefit rather than patient-reported evidence of benefits. A secondary aim of this study, therefore, was to follow patients during the first few days following receipt of the consultation recording to document, from the patient's perspective, the benefits realized from listening to the recording.

Methods

Oncologist sample

The 18 participating oncologists included eight radiation oncologists from the British Columbia Cancer Agency, Vancouver, Canada who specialize in breast cancer, six medical oncologists from the Tom Baker Cancer Centre in Calgary, Canada who treat prostate cancer, and three medical oncologists and one radiation oncologist who treat patients with breast cancer at CancerCare Manitoba in Winnipeg, Canada. Given that our primary research aim was to address the barriers and facilitators of consultation recording use to enhance practice uptake, we selected our patient and oncologist sample to accomplish the following:

- (i) Have a diverse but manageable number of sites to be able to have different contexts, that is, a breadth of contextual influences, from which to learn;
- (ii) Involve as many oncologists as possible from each site to enhance the likelihood of maintaining consultation recording use following the data collection phase;
- (iii) Involve an identified oncologist 'champion' in each site who can promote consultation recording practice;
- (iv) Include patients with breast and prostate cancer because these two tumor types have the strongest consultation recording evidence base.

All of the oncologists who were approached to participate provided informed consent to do so; none refused. The primary nurses for the study oncologists were also invited to record their initial meetings with the patients, but all declined.

Patient sample

Eligible patients included women and men with a confirmed primary diagnosis of nonrecurrent breast or prostate cancer, respectively, who presented to a tertiary oncology center for their initial, postsurgical breast adjuvant treatment or initial, postdiagnostic prostate treatment consultation with a participating oncologist. All patients were 18 years of age or older, able to read and communicate using the English language, and without brain metastases or other cognitive impairment that would preclude provision of free and informed consent to participate. Patients could not participate if they did not have access to a computer—or access to an individual who would assist

them on a computer—for the purpose of listening to the recorded consultation.

Study procedures

The study protocol was approved by the institutional review boards for human subjects research at the Universities of British Columbia, Calgary and Manitoba, and by the three participating cancer centers. All patients and oncologists provided informed, written consent to participate. The study coordinator held a conference call with the research associates (RAs) at quarterly intervals to address study-related concerns.

Prior to implementation, the principal investigator (PI) traveled to each site to introduce the study at either grand rounds or disease site rounds, review the data collection protocol with participating staff, and obtain consent form signatures from the oncologists. To capitalize on the implementation knowledge gained at each location, implementation was staggered, that is, data collection commenced in a subsequent city only after data collection and analysis had been completed at the current city.

The accrual procedures varied somewhat across the three cities depending on the requirements of the ethics review committees and the clinic procedures for contacting patients to schedule initial consultations. However, the general accrual procedures were as follows: the RA or scheduling clerk identified those patients of the participating oncologists who met the eligibility criteria. The scheduling clerk or the RA contacted eligible patients via telephone or letter within 5–14 days prior to the day of the consultation to explain the study and obtain verbal consent to participate. If the scheduling clerk contacted the patient, then the clerk gave the RA's contact information to any patient interested in participating in the study, and the patient then contacted the RA to express their intent to participate.

On the day of the consultation, the RA met the patient in the clinic to acquire informed, written consent to participate and to complete the patient sociodemographic and disease information form. The consultations were recorded using a hand-held digital recorder. The RA ensured that the recording materials were appropriately placed in the consultation room, and the oncologists were responsible for starting the recording process. After the consultation, the RA immediately downloaded the consultation on to a laptop computer and then on to a USB key (i.e., memory stick) that was handed to the patient, with verbal and written instruction on how to download and listen to the recording on a computer.

The RA contacted the patient 2 days postconsultation by telephone to learn whether the recording was listened to and, if it was, to administer the Digital Recording Use Semi-Structured Interview (DRUSSI) [1,2]. The RA contacted the patient at 7 days postconsultation to administer the DRUSSI once more to capture a more complete account of consultation recording use and benefits therein. The DRUSSI has evolved over successive research studies conducted by the present research team. Although the term DRUSSI was coined for the present study, a variant of the DRUSSI (the Audiotape Questionnaire) was first used by the team in the late 1990s. This instrument was called the Audiotape Use and Satisfaction Questionnaire

in subsequent team studies. The DRUSSI is used to capture the number of times a patient listens to the entire recording and portions of the recording, and the number of different people who listen to the recording and the relationship of these individuals to the patient (e.g., spouse/partner, friend, family member, relative, doctor). In addition, patients are asked 'On a scale of 0 to 100, where 0 = extreme dislike of the recording, 100 = extreme liking of the recording, and 50 = neutral, do not like or dislike the recording, how do you rate the recording overall?' Questions added to the DRUSSI for the current study were the following: 'When did you listen to the recording?' 'When did you make your treatment decision?' and 'Did the recording assist in making your treatment decision?' If the last question was answered affirmatively, then patients were asked 'How did the recording help you make your decision?' In addition, a final open-ended question was asked: 'Would you please describe, in your own words, your overall experience with, and opinion about, the recording?' The time for completion of the DRUSSI was 15-30 min, depending on the level of detail provided in response to the open-ended questions. Nearing the close of the 7-day postconsultation DRUSSI, the RA asked patients for their permission to share their consultation recording feedback in a letter given to each oncologist incorporating the comments of all the oncologist's patients.

At approximately 2 months following the participation of the final patient at each location, the PI met with the medical personnel involved in the implementation to solicit feedback regarding the successes and challenges realized. In the days immediately preceding this staff meeting, the oncologists were given their patient feedback summary letter. To enable oncologists to appreciate the feedback given to other oncologists, each oncologist also received a summary document that highlighted the feedback of all patients.

A patient focus group was held on the day after the staff meeting. The goal of the focus group was to share and validate the DRUSSI results. The focus group was explained in the patient consent form, and there was a separate consent box in the form for patients to indicate whether they wanted to participate in the focus group or not. Patients who agreed to the focus group were contacted at the end of the implementation period by telephone, given the time and location details, and asked again whether they wanted to participate. In Winnipeg, at the time of study consent, 45 of the 77 women wanted to be contacted later for the focus group; when contacted later, only 2 of the 45 women accepted the invitation (most of the women were on chemotherapy or radiation therapy treatment), so the focus group was canceled. The local RA and the PI led the Calgary and Vancouver groups. Fifteen patients attended in Calgary and 17 in Vancouver. One oncologist was present at the Calgary meeting. The entire oncologist group was not invited out of concern that patients might not be forthcoming in their responses knowing their oncologist was in attendance. To promote full, honest expression, the focus groups were not recorded. Instead, two RAs took notes, and these notes were later reviewed by two RAs and the PI to identify salient themes.

At one month following the last of the post-implementation oncologist staff review meetings, a meeting of the research team was held to review the findings of the (i) post-implementation oncologist staff meetings, (ii) patient focus groups, and (iii) data from the DRUSSI to identify, using the team's PARIHS-based conceptual framework, the fundamental evidentiary, contextual, and facilitative components of consultation recording implementation.

Data management

A relational database was created using SPSS for Windows (Version 15) to store the quantitative data. This database, copies of all consultation recordings, all patient sociodemographic, illness, and interview data, and oncologist interview data, was stored on a central server at the PI's institution, with access limited to specific users at the discretion of the PI. This server is backed up daily.

During the implementation period, the local site coordinator contacted each oncologist and primary nurse after approximately five of the oncologist's patients had participated, for the purpose of finding out if the study was progressing smoothly, to document oncologist/nurse feedback on the study and to address any concerns. The aim was to identify and remedy as quickly as possible any unforeseen events or circumstances that might hamper the successful implementation of the intervention. The local site coordinator kept a written record of these events and circumstances and the actions taken to address them. Meetings of the PI, data manager, and project staff were held whenever necessary to review progress and discuss concerns.

After each patient received their recorded consultation on a USB key, the RA downloaded the recording as a file to a key-protected internet website and then deleted the file that was saved on the laptop computer as a means of transferring the recorded consultation to the USB key. The password-protected website was accessible to only the program coordinator and the PI during the implementation phase. To protect the private nature of the recorded consultations, the USB keys were printed with 'Patient Copy' along one side and a study e-mail address along the other side. By labeling the USB keys in this manner, the USB keys were less likely to be misplaced, and any individual, including the patient, was less likely to use the USB key for another purpose. In addition, should the USB key become lost, its return would be facilitated by the inclusion of the website address. To our knowledge, no USB keys were misplaced during the course of this study. Interview and focus group notes were kept anonymous. Patient names were not stored in data files (hard copy records linking patient names with computer identifiers were stored in a separate location).

The post-implementation oncology staff interviews, patient focus group data, and DRUSSI interview data were analyzed by the study PI, study coordinator, and one of the RAs, who performed a content analysis of the data (the telephone administration of the DRUSSI precluded recording, but the RAs were instructed to take detailed notes that were also analyzed and summarized

into salient themes). Having three coders helped to minimize coding bias. The content analysis of the data was performed using an inductive approach and using open coding and constant comparative analysis. Successive meetings of the three coders were held to discuss emerging themes in the data.

Results

Sample

Of the 363 patients approached to participate in this study, 85 did not satisfy the inclusion criteria. Of these, 32 did not speak English, 3 had dementia, and 50 did not have access to a computer (the vast majority of these individuals were over 75 years of age). Of the remaining 278 patients, 49 refused the invitation to participate, yielding a total of 229 patients who provided informed consent. Reasons given for not wanting to participate included having insufficient time to do so, not wanting to be contacted at home, not wanting a copy of the consultation recording available to anyone else, feeling too overwhelmed, anxious or sick, being too busy, or not seeing benefit because they had a previous unrelated cancer diagnosis and therefore had plenty of existing information. Refusal statistics were available for Calgary and Vancouver but not for Winnipeg where the scheduling clerk rather than the RA contacted the patients initially. In Winnipeg, all the patients who contacted the RA after having been given the RA's telephone number by the scheduling clerk chose to participate in the study. All of these Winnipeg patients satisfied the inclusion criteria for participation, so it is assumed that those patients who did not speak English, any with dementia, and those without access to a computer self-selected out of the study, that is, chose not to contact the RA. Of the 229 patients who signed consent forms, all but one patient completed the study (one patient in Vancouver did not remain after the consultation to receive her USB key, and she could not later be reached by telephone), yielding a final sample of 228 patients who completed the study. The demographic and disease information for the patient sample is provided in Table 1.

Consultation recording use and satisfaction

Of the 228 patients who completed the study, 157 (68.9%) listened to at least a portion of the recording within the first week following the consultation, whereas 71 patients (31.1%) did not listen to the recording at all. Closer examination of listening habits showed that patients tended to listen to the recording in its entirety. Among the whole sample, 28.5% of patients listened to the entire recording within 2 days postconsultation, 24.1% of patients listened to the entire recording within the 3–7 days postconsultation period, 14.5% listened to the entire recording within the first 2 days postconsultation and during the 3-7 days postconsultation interval, and 1.8% of patients listened only to a portion of the recording within 1 week postconsultation. Patients listened to the entire recording a mean of 2.0 times (SD = 1.8, max = 8times) and a portion of the recording an average of 21.7 (SD = 1.3) times.

Table 1. Patient demographic and disease information (n = 228)

Variable	No. of patients (%)
Age, years	
(Mean = 59.8, SD = 15.3, range = 36–86)	
Disease site	
Breast	174 (76.3)
Prostate	54 (23.7)
Education	
<high school<="" td=""><td>37 (16.2)</td></high>	37 (16.2)
High school only	50 (21.9)
>High school	138 (60.5)
Missing	3 (1.3)
Marital status	
Married/partnered	159 (69.7)
Widowed/divorced/separated	43 (18.9)
Never married	23 (10.1)
Missing	3 (1.3)
Residence	
Urban	177 (77.6)
Rural	50 (21.9)
Missing	I (0.4)
Breast cancer	
Surgery	
Lumpectomy	120 (69.0)
Modified radical mastectomy	42 (24.1)
None at time of consultation	9 (5.2)
Missing	3 (1.7)
Node dissection	
Sentinel node dissection (SND) only	83 (47.7)
Axillary node dissection (AND) only	30 (17.2)
Both SND and AND	27 (15.5)
Ductal carcinoma in situ	25 (14.4)
Missing/unavailable (only core biopsy)	9 (5.2)
Disease stage	
Stage 0	25 (14.4)
Stage I	78 (44.8)
Stage II	52 (29.9)
Stage III	8 (4.6)
Stage IV	2 (1.1)
Missing/unavailable	9 (5.2)
Prostate cancer	
Prostate-specific antigen, ng/mL	
(Mean = 11.2, SD = 10.4, range = 0.4-62.5)	
Gleason score	
(Mean = 7.2, SD = 1.0, range 6-9)	
Disease stage	
Stage I	15 (27.7)
Stage II	24 (44.4)
Stage III	10 (18.5)
Missing	5 (9.3)

There were 92 (58.6%) patients who had someone else listen to at least a portion of the recording. The average number of other persons who listened to the recording was 0.8 (SD=0.5, range=1-6). The most common individual to listen to the recording was the patient's spouse/partner (50%), followed by a family member (45.1%), friend (4.1%), or another doctor (0.8%).

For the 71 patients who did not listen to the recording, the reasons given for not listening included the following: too busy (n=18, some of these patients planned to listen later), unnecessary (n=15), computer malfunction (n=7), reliant on someone else's computer (n=6), too overwhelmed (n=5), oncologist improperly recorded the consultation (n=4), too sick (n=2), want to move on (n=1), and prefer a transcribed version (n=1). Six patients did not provide a reason, and six patients could not be reached at follow-up.

Patients rated the consultation recording intervention highly during the 7-day postconsultation interview. Of the 157 patients who listened to the recording, 70 (44.6%) rated the intervention 100 out of a possible 100, that is, the highest, most positive, score. There were 77 (49.0%) patients who rated the intervention between 75 and 99, 9 (5.7%) patients who rated it between 50 and 74, and 1 (0.6%) patient who rated the intervention 49 points or fewer. The mean favorableness rating was 93.8 out of 100 (SD=13.7, range=30–100), indicating highly positive regard for the recording. Forty-two percent of patients expressed that they made their own treatment decision, and 29.3% of patients said the consultation recording helped them in arriving at a treatment decision.

Consultation recording benefits

Results from the analysis of the two postconsultation patient DRUSSI interviews showed four main areas of benefit: (i) anxiety reduction; (ii) enhanced retention of information; (iii) better informed decision making; and (iv) improved communication with family members.

Anxiety reduction

Given the degree of patient uncertainty during the diagnostic and treatment planning period, it is not uncommon for patients to enter the initial treatment consultation feeling anxious. At times, the level of anxiety can be severe, with patients feeling that they are disassociating from the consultation or 'blanking out'. Knowing that one's consultation is being recorded allows patients to relax more easily during the consultation, knowing that they will be able to listen to their recording in the future. For some patients, having a recording eliminates the need to take notes during the consultation. The patient exemplars in Table 2 (and subsequently in Tables 3–5) capture these findings, as reported by different patients.

Enhanced retention of information

The patients expressed that listening to the consultation recording helped them to remember disease and treatment information they had forgotten. Patients receive detailed information during the initial consultation, and the recording helps to improve recall and reduce memory decay (Table 3).

Better informed decision making

As shown in Table 4, many patients expressed that the quality of their treatment decision and their level of satisfaction with the chosen treatment were enhanced by the consultation recording. For some patients, the recording was especially helpful for helping them to decide on whether or not to participate in a clinical trial.

Improved communication with family members

Patients expressed that the consultation recordings facilitated communication about their disease and treatment with family members (Table 5). Many patients reported struggling with what to say to family members when asked about their disease because they themselves were uncertain as to what was said to them during their consultation. The recordings helped patients impart information to family members

Table 2. Anxiety reduction—patient exemplars

I found the recording very helpful. I was told originally would not need radiation but when I met with Dr. ______ he told me I needed it...Once he told me that my mind went blank... very thankful I had the recording.

Best thing you can give a patient, you're so distracted and upset, patients need this to remember or at least to go back and listen.

A very upsetting experience... found it very helpful to have it [the recording]. I had to play it back so I could remember. There was a lot of information that I was not aware of. Nice to know the recording will be there. Usually after a doctor's appointment I go to the car and make notes; didn't have to do that, I could just relax.

I was not expecting the diagnosis and treatment options I was given so I was feeling very overwhelmed with the information. Recording allowed me to listen to the doctor instead of taking notes. The tool is very useful and I will listen now that I am in a better state of mind.

If you haven't been through the experience before and you are scared, it relaxes you to have the recording to listen to again.

You listen at the consultation and afterwards I had so much running through my head. The first night I had trouble going to sleep, so I got up and listened to the recording. It really helped me settle down.

Table 3. Information retention—patient exemplars

Hearing it again helps so much. Every time I listen to it I get something else out of it. I think the recording is a super idea. You take everything in but then find you cannot remember anything. I will probably listen to it a few times in the next few weeks.

So happy to have the recording; was applying information to the wrong thing. Things I forgot, my mind is whirling so the recording is very beneficial. I missed the measurements in the appointment but was able to get it from the recording.

Great to have this recording, you think you are going to remember everything but there is so much information given. Should be used for all types of illness (not just cancer) as people are so in shock that you don't always hear what is being said.

Really like the recording; doctor had talked about the liver and I thought there was something on the liver but after listening again I realized the doctor said it was clear.

An amazing piece of very crucial information that you can hear over again and get what was given in the office. A lot of information was given and I was able to go back and listen... able to share with family, and especially if no medical background you're able to look up and find out meaning of things said. I've told family and friends about it who think it is a wonderful idea. I feel this is the most important piece of information given so far; cannot say enough good about it. Sometimes you question what you may or may not have heard.

It re-emphasized the pros and cons and side effects; So many things I had already forgotten and this helped me remember. I felt that after listening to it the first time, it put everything into perspective for me.

I couldn't believe how much I had forgotten. I had even forgotten some of the questions I had asked.

Table 4. Informed decision making—patient exemplars

Listening to Dr. _____ about the clinical trial in the appointment, I wasn't sure what treatment I wanted, but once I listened to the recording I knew it was not for me. I decided to go the other way. The recording has been wonderful and excellent.

Helped with treatment decision by giving more information, and reinforced what the surgeon had recommended... Why would someone not have this done? It is such a good idea.

Helped with the treatment decision as I thought I remembered the doctor saying something but not sure, so able to go back and listen again. The doctor tells numbers and hard to remember but able to hear again... I had doubted myself but I was able to listen and confirm what I thought I heard... I cannot say enough about it. It helped with treatment decision very much!. I was unsure whether to have oral chemotherapy and this definitely helped with that.

I couldn't remember everything the doctor said, so listening definitely helped me make my decision. You are in a state of nervousness during consultation. The doctor mentions lots of percentages. When I go to explain to other people, I can't remember all the specific points. I think everyone should have a recording done.

During consultation and listening to the recording made me aware of questions I need to ask my surgeon. I thought I had made a decision, but now I am back to some uncertainty.

Invaluable experience, the recording clarified all the information received. It helped to clear up some confusion around treatment timelines, wait time for treatment, and duration of treatment.

The information on the recording about the clinical trial presented to me during the consultation was instrumental in my decision to participate.

Table 5. Communication with family members—patient exemplars

Thought it was great, good to listen again so that when people ask questions we know how to answer. If we didn't think the doctor told us that or just didn't remember we go back and listen and we found that the doctor did give the answer.

I found it very useful to be able to play for my family. My daughters thought it was a wonderful idea seeing as how they do not live here and could not attend the consultation. I just don't retain all the info, I went to explain the consultation to my partner and I couldn't remember the specific percentages. Being in the medical profession he was asking specific questions; it is easier for him to just listen to the recording.

Fabulous, I had forgotten some things... I took it to my GP and she thought it was absolutely fantastic. She didn't know this was offered. Now she knows what to expect from my radiation treatments. I left it there and she had the nurse download it so that she could finish listening to it. I am going back later this week to see her again and I will pick it up. One down side is that I can't figure out how to forward it to my daughters. I think the file is too big and I need help on how to compress it.

My wife was unable to attend the consultation. Listening to the recording at home with her generated the most open conversation we've had about this diagnosis.

My children found the information on the recording presented in a very orderly fashion. They also stated it was helpful to hear the same information their parents had heard.

Prior to listening to the recording my wife and I talked about the consultation and what each remembered and our interpretation of the information. After listening everything was very clear. It was obvious to both of us how much we had misinterpreted.

Psycho-Oncology 22: 1273-1282 (2013)

unable to attend the consultation. In some cases, these patients lived a far distance from the family member. One patient remarked, during a focus group session, that he found great benefit in being able to e-mail the consultation to his daughter—a nurse—who lived overseas, so that she could be more involved in his treatment and care.

Four additional findings are worth noting. First, there were many patients who captured multiple benefit areas in their comments:

[The recording] reinforced the [treatment] decision I made...was able to understand the need for chemotherapy, the estrogen and progesterone. Wonderful idea, children would like to listen to it when time permits... feel lucky to have the opportunity to have the consult recorded because I would not have remembered everything... Would like to have had the resident recorded as well; would like to have had a recording when I met with the surgeon.

Prior to the consultation I thought I had made a decision to have radiation treatments. Now I am not certain. The recording is helping me shape my decision... The two of us hear different things and ask different questions... Having the recording is very useful. The whole thing is very stressful. I can handle stress, but sometimes you just won't hear everything due to the stress... This will be especially good for someone who goes to the appointment alone... Sometimes you hear what you want to hear, or you don't hear something. So it is useful to listen to the consult again.

I thought I was very present during the consult, but when I listened to the recording I was surprised at how much I had forgotten If a family member asks about what the doctor said or what is it all about I would give then the recording and just be done with it. Then I don't have to keep repeating the same info over again... The consult was very succinct. It is a great tool to have the recording because we are stressed during the consult and don't hear everything.

Second, patients expressed value in having other types of consultations recorded:

Very good idea, should be done on all first visits, wished I could have had resident recorded as well. Every appointment is so important with so much information... wish they could all be taped. Would liked to have had it when meeting with surgeons, I was alone and felt at a disadvantage with four doctors, I would like to have been able to record it, I was told by the resident five minutes before seeing Dr. _____ that I had cancer and was a bit numb and a recording would have been helpful.

Would like to have the recording from the very beginning—from surgeon to oncologist. Would be good to have if children ever want to know more about my illness.

Third, two patients remarked that consultation recordings would reduce the number of phone calls to the clinic to clarify information conveyed during the consultation. These comments support the anecdotal remarks of two of the primary nurses who expressed receiving fewer phone calls from patients who had received a consultation recording.

Very positive and helpful experience. Very informative for the patient. When you hear something you are not expecting to hear, it can knock you off guard and then you realize you missed a bunch of dialogue following that point and you forget questions you meant to ask; I think it would save time for physicians, in that they would get less phone calls from patients having follow up questions if the patient has the recording to refer back to.

It is a very good idea.... Good for answering questions so that you don't have to call the clinic back as often.

Fourth, although the findings were overwhelmingly in favor of the consultation recording intervention, there were a minority of patients who did not regard the recording as valuable:

I had my niece come with me as a second set of ears. I did listen to the recording. As it was fairly clear from the consultation what needed to happen, the recording didn't add any new information and wasn't very useful. I question the usefulness to a certain number of people and the cost of the USB keys, but it would be good for some people.

No real benefit to me. Didn't feel like I had forgotten anything or picked up anything new, when I listened to it. Everything was repeated often during the consultation.

My consultation was straight forward and definite. Had my case been something where I had to decide which options to choose, I may have listened to it.

Implementation of consultation recording practice

Eight fundamental components of successful transfer and uptake of consultation recording practice were identified during this study. These components have been organized (presented in Table 6) according to the PARIHS implementation framework.

With respect to 'Evidence', we found that it is essential to provide oncology staff with confirming evidence of consultation recording benefits. Oncologists, their primary nurses, and administrative team leaders have differing personal views as to the value of consultation recordings and differ in their assessment of existing evidence. In fact, the majority of oncology professionals are unaware of the empirical evidence in favor of consultation recording practice. These individuals need to be sufficiently informed to support a change in practice to allow uptake of consultation recording use into practice. The Cochrane Collaboration systematic review of consultation recording use is an essential component of the evidence base and should be given to the oncology professional team.

With respect to 'Context', it is critical that a 'champion' for consultation recording practice be identified from within the oncology team. This champion should be a disease site group chair or other respected individual who has either the administrative or social power—preferably both—to champion the cause of consultation recording use. This individual needs to be passionate about the benefits of consultation recording practice and

Copyright © 2012 John Wiley & Sons, Ltd.

Psycho-Oncology 22: 1273-1282 (2013)

Table 6. Fundamental components of consultation recording implementation

Evidence

1. Provide the oncology staff with confirming evidence of consultation recording benefits

Contex

- 2. Identify a disease site group chair or other respected individual to 'champion' the cause of consultation recording use and assume responsibility for implementation activities
- 3. Meet with disease site leaders, chief nursing officers, and chief executive officer to secure administrative support for consultation recording practice
- 4. Secure administrative commitment of financial resources to pay for consultation recorders and USB keys
- 5. Obtain administrative commitment of staff resources to manage the recording of consultations and the timely downloading of consultations onto USB keys
- 6. Identify the person(s) responsible for notifying the patient of the option to receive a consultation recording, placing the digital recorder properly in the consultation room, and transferring the recording to a computer and then to a USB key
- 7. Provide organizational clarity about medicolegal aspects of recording consultations

Facilitation

8. Following the implementation phase, provide participating oncologists with a letter summarizing the consultation recording benefits realized by their patients

be willing to assume responsibility for implementation activities. The existence of a 'champion' is necessary but insufficient for successful implementation. The support of entire disease site groups, including the primary nurses of the oncologists, is required, as is support from those occupying senior administrative positions. Senior administrative personnel who have the power to allocate funds to allow for implementation of consultation recording practice are necessary. For example, in the present study, implementation was highly successful in one particular center because of the commitment of a disease site group chair who championed the cause of consultation recording practice. This individual had earned the respect of the entire disease site group and worked with fellow oncologists to establish consultation recording practice as a priority. At the completion of the implementation phase, despite support from the disease site group to continue recording consultations, recording stopped because of a lack of resources to pay for digital recorders and USB keys. A spending freeze at the highest levels of provincial government had caused the implementation efforts to grind to a halt, despite the strong evidence base, presence of a champion, and support from the highest administrative levels within the cancer center. Fortunately, the local champion was later able to secure funds from pharmaceutical companies and private donors to pay for the recorders and USB keys, enabling the consultation recording practice to continue.

Two other 'Context' factors are considered essential for successful implementation. First, the oncology team of providers needs to assign responsibility for notifying patients of the option to receive a consultation recording. This individual is most likely to be a scheduling clerk, a ward clerk, or a primary nurse. Responsibility must also be assigned for ensuring that the recording equipment is set up in the consultation room, for downloading the recording to a computer and then to a USB key, and giving the USB key to the patient. Second, any medicolegal concerns should be addressed, as well as issues of who 'owns' the recording, whether or not the cancer center needs to retain a copy of the recording, data storage issues, and privacy concerns. In the present study, medicolegal concerns were raised at each cancer center; we sought legal opinion from the Canadian Medical Protective Association to satisfy the concerns of all parties.

With respect to 'Facilitation', behavior learning theorists have long known the value of providing positive reinforcement of behaviors you want to increase in frequency. Reinforcement that is meaningful and timely is more likely

to be effective. It is for this reason that, following the implementation phase, the oncologists were provided with a feedback letter summarizing the consultation recording benefits realized by their patients. This letter was a way to not only thank the oncologists for their willingness to record their consultations but to let them know that their participation was greatly appreciated by patients. In the present study, we feel that the feedback letters served to facilitate the oncologists' commitment to continue recording patient consultations on a more regular basis.

Discussion

The present findings build on previous research in this area, providing further evidence in support of providing newly diagnosed cancer patients with recordings of their initial treatment consultations. Similar to previous studies [12,13], approximately two thirds of patients listened to their recorded consultations, whereas one third of patients did not. Although the listening habits of those with recordings have changed very little over the past decade, ratings of satisfaction with the recordings have increased. In the present study, the mean value rating for the recording was 93.7 out of 100. This indicates a trend toward an increasing value of this intervention; our previous randomized controlled trials of consultation recording benefits in breast [13] and prostate [12] cancer samples generated mean benefit scores of 83.9 and 83.0, respectively. Future studies examining the impact of consultation recording on patientreported outcomes should include measures of the four categories of patient benefit realized in this study—anxiety, information recall, informed decision making, and enhanced communication.

Despite consistent reports of high value and significant patient benefit associated with consultation recordings, uptake into routine oncology practice has been slow. Additional implementation studies are needed to target factors with the potential to enhance the rate of uptake. The fundamental implementation factors presented here are a useful starting point for future consultation recording studies, and the PARIHS framework may be helpful in identifying other factors instrumental for implementation success. With respect to the 'Evidence' criterion of the PARIHS framework, clinical practice guidelines are valuable evidence in the effort to promote consultation recording practice. Only in the past few years have practice guidelines been developed in psycho-oncology. In Canada, for example, a psychosocial guideline governing the psychosocial

Copyright © 2012 John Wiley & Sons, Ltd.

Psycho-Oncology 22: 1273-1282 (2013)

assessment and care of cancer patients was recently published [38]. The incorporation of consultation recording practice as a recommendation in this and other practice guidelines is an important implementation goal.

'Context' is an important framework consideration. Future studies should spend sufficient upfront time detailing the unique characteristics of the oncology context in which consultation recording is to take place. Interviews and meetings with oncologists, oncology nurses, scheduling clerks, and administrative staff are invaluable for garnering support for consultation recording use. Special attention should be given to the role of the RA in executing consultation recording research. In future randomized controlled trials, with the goal of incorporating consultation recordings in routine practice, particular attention should be given to having the RA introduce the consultation recording protocol seamlessly, in a manner that causes minimal work disruption for oncologists, nurses, and other staff.

'Facilitation' may need to be considered more broadly if implementation efforts are to be more successful. To date, most of the implementation efforts have been directed at encouraging oncology staff to record consultations so that patient value and benefit can be demonstrated. It may prove equally beneficial to systematically examine the role of patient advocacy groups, the lay public, and the media in promoting consultation recording use. A strong patient and public voice may go a long way toward increasing the patient demand for consultation recordings. Cancer advocacy networks may be powerful allies in promoting the dissemination of consultation recording practice, and they can exert a powerful and positive influence on the media, government, and research funding bodies.

The stipulation by one of the local access committees that we use scheduling clerks rather than clinic nurses as the point of first contact with patients was a study limitation, hindering our ability to track the number of patients that were contacted to participate, as well as the acceptance rate of those contacted. Use of scheduling clerks is advisable outside of the research arena because clerks can prime patients several days prior to their consultation regarding the availability of consultation recording. Within a research study, however, where the numbers of protocol accepters and rejecters need to be tracked, this approach actually hinders the research enterprise if the clerk requires the patient to contact the research nurse if additional study information is sought. If scheduling clerks are to be used, it is suggested that they ask the patient's permission to provide the patient's contact information to the research nurse, thereby allowing the research nurse to effectively track study enrolment.

In conclusion, our study showed that a majority of the patients listened to at least part of the consultation recording and as a result, experienced reduced anxiety, enhanced retention of information, better informed decision making, and improved communication with family members. Given the positive evidence base for providing cancer patients with recordings of important medical consultations, more implementation research is needed to facilitate the transfer and uptake of this intervention so that more patients may realize the benefits that consultation recordings provide not only for themselves but also for family members and significant others as well.

Acknowledgements

This study was supported by research grant # 87024 from the Knowledge Synthesis and Exchange Committee of the Canadian Institutes of Health Research (CIHR) and research grant # 89840 from the Canadian Breast Cancer Research Alliance/CIHR. Lesley F. Degner was supported by a Research Chair from the Canadian Health Services and Research Foundation and the CIHR.

References

- McGregor S. What information patients with localized prostate cancer hear and understand. Patient Educ Couns 2003;49:273–278. DOI: 10.1016/S0738-3991(02)00182-9
- Sowden AJ, Forbes C, Entwistle V, Watt I. Informing, communicating and sharing decisions with people who have cancer. *Qual Health Care* 2001;10:193–196. DOI: 10.1136/ qhc.0100193
- Wong F, Stewart DE, Dancey J et al. Men with prostate cancer: influence of psychological factors on informational needs and decision making. J Psychosom Res 2000;49:13–19. DOI: 10.1016/S0022-3999(99)00109-9
- Cegala DJ, Bahnson RR, Clinton SK et al. Information seeking and satisfaction with physician–patient communication among prostate cancer survivors. Health Commun 2008; 23:62–69. DOI: 10.1080/10410230701806982
- Jansen J, Butow PN, van Weert JCM et al. Does age really matter? Recall of information presented to newly referred patients with cancer. J Clin Oncol 2008;26:5450–5457. DOI: 10.1200/JCO.2007.15.2322
- Husson O, Mols F, van de Poll-Franse LV. The relation between information provision and health-related quality of life, anxiety and

- depression among cancer survivors: a systematic review. *Annals Oncol* 2011;**22**:761–772. DOI: 10.1093/annonc/mdq413
- Bruera E, Pituskin E, Calder K, Neumann CM, Hanson J. The addition of an audiocassette recording of a consultation to written recommendations for patients with advanced cancer. Cancer 1999;86:2420–2425. DOI: 10.1002/(SICI)1097-0142
- Deutsch G. Improving communication with oncology patients. Clin Oncol 1992;4:46–47.
 DOI: 10.1016/S0936-6555(05)80774-5
- 9. Dunn SM, Butow PN, Tattersall MHN *et al.* General information tapes inhibit recall of the cancer consultation. *J Clin Oncol* 1993;**11**:2279–2285.
- Ford S, Fallowfield L, Hall A, Lewis S. The influence of audiotapes on patient participation in the cancer consultation. *Eur J Cancer* 1995;31A:2264–2269. DOI: 10.1016/0959-8049(95)00336-3
- Hack TF, Pickles T, Bultz BD, Degner LF, Katz A, Davison BJ. Feasibility of an audiotape intervention for patients with cancer: a multicenter, randomized, controlled pilot study. *J Psychosoc Oncol* 1999;17:1–15.
- Hack TF, Pickles T, Bultz D, Ruether JD, Degner LF. Impact of providing audiotapes of primary treatment consultations to men with

- prostate cancer: a multi-site, randomized, controlled trial. *Psycho-Oncology* 2007;**16**: 543–552. DOI: 10.1002/pon.1094
- Hack TF, Pickles T, Bultz BD et al. Impact of providing audiotapes of primary adjuvant treatment consultations to women with breast cancer: a multi-site, randomized, controlled trial. J Clin Oncol 2003;21:4138–4144. DOI: 10.1200/JCO.2003.12.155
- 14. Hack TF, Whelan TJ, Olivotto IA et al. Standardized audiotape versus recorded consultation to enhance informed consent to a clinical trial in breast oncology: a feasibility study. Psycho-Oncology 2007;16:371–376. DOI: 10.1002/pon.1070
- Hobgin B, Fallowfield L. Getting it taped: the "bad news" consultation with cancer patients. Br J Hosp Med 1989;41:330–333.
- Johnson AA, Adelstein DJ. The use of recorded interviews to enhance physician–patient communication. J Cancer Educ 1991;6:99–102.
- 17. McHugh P, Lewis S, Ford S et al. The efficacy of audiotapes in promoting psychological well-being in cancer patients: a randomised, controlled trial. Br J Cancer 1995;71:388–392. DOI: 10.1038/bjc.1995.79
- North N, Cornbleet MA, Knowles G, Leonard RC. Information giving in oncology: a preliminary study of tape-recorder use. Br J Clin

- Psychol 1992;**31**:357–359. DOI: 10.1111/j.2044-8260.1992.tb01005.x
- Reynolds PM, Sanson-Fisher RE, Poole AD, Harker J, Byrne MJ. Cancer and communication: information giving in an oncology clinic. *Br Med J* 1981;282:1449–1451.
- Stephens MR, Gaskell AL, Gent C et al.
 Prospective randomized clinical trial of providing patients with audiotape recordings of their oesophagogastric cancer consultations. Patient Educ Couns 2008;72: 218–222.
- Tattersall MHN, Butow PN, Griffin AM, Dunn SM. The take-home message: patients prefer consultation audiotapes to summary letters. *J Clin Oncol* 1994;12:1305–1311.
- McClement SE, Hack TF. Audio-taping the oncology treatment consultation: a literature review. *Patient Educ Couns* 1999;36:229–238. DOI: 10.1016/S0738-3991(98)00095-0
- Pitkethly M, MacGillivray S, Ryan R. Recording or summaries of consultations for people with cancer (Review). *Cochrane* Collab 2008;(3). DOI: 10.1002/14651858
- Scott JT, Harmsen M, Prictor MJ, Entwistle VA, Sowden AJ, Watt I. Recording or summaries of consultations for people with cancer (Review). *Cochrane Collab* 2007;(2).
- Tattersall MH, Butow PN. Consultation audio tapes: an underused cancer patient information aid and clinical research tool. *Lancet Oncol* 2002;3:431–437. DOI: 10.1016/S1470-2045 (02)00790-8

- van der Meulen N, Jansen J, van Dulmen S, Bensing J, van Weert J. Interventions to improve recall of medical information in cancer patients: a systematic review of the literature. *Psycho-Oncology* 2008;**17**:857–868. DOI: 10.1002/pon.1290
- 27. Ong LML, Visser MRM, Lammes FB, van Der Velden J, Kuenen BC, de Haes JC. Effect of providing cancer patients with the audiotaped initial consultation on satisfaction, recall, and quality of life: a randomized, double-blind study. *J Clin Oncol* 2000;18: 3052–3060.
- Davison BJ, Degner LF. Empowerment of men newly diagnosed with prostate cancer. Cancer Nurs 1997;20:187–196.
- Hack TF, Degner LF. Audio-recording important consultations for patients and their families-putting evidence into practice. In Handbook of Communication in Oncology and Palliative Care, Kissane DW, Bultz BD, Butow PM (eds). Oxford University Press: Oxford, 2010; 351–360.
- Eccles MP, Mittman BS. Welcome to Implementation Science. *Implement Sci* 2006;1:1.
 DOI: 10.1186/1748-5908-1-1
- Rycroft-Malone J. The PARIHS framework a framework for guiding the implementation of evidence-based practice. *J Nurs Care Qual* 2004:19:297–304.
- 32. Harvey G, Loftus-Hills A, Rycroft-Malone J *et al.* Getting evidence into practice: the role and function of facilitation. *J Adv Nurs*

- 2002;**37**:577–588. DOI: 10.1046/j.1365-2648.2002.02126.x
- Kitson A, Harvey G, McCormack B. Enabling the implementation of evidence based practice: a conceptual framework. *Qual Health Care* 1998;7:149–158. DOI: 10.1136/ qshc.7.3.149
- McCormack B, Kitson A, Rycroft-Malone J, Titchen A, Seers K. Getting evidence into practice: the meaning of 'context'. J Adv Nurs 2002;38:94–104. DOI: 10.1046/j.1365-2648.2002.02150.x
- Rycroft-Malone J, Kitson A, Harvey G et al. Ingredients for change: revisiting a conceptual framework. Qual Saf Health Care 2002,11:174–180. DOI: 10.1136/qhc.11.2.174
- Rycroft-Malone J, Harvey G, Seers K, Kitson A, McCormack B, Titchen A. An exploration of the factors that influence the implementation of evidence into practice. *J Clin Nurs* 2004;13:913–924. DOI: 10.1111/j.1365-2702.2004.01007.x
- Helfrich CD, Damschroder LJ, Hagedorn HJ et al. A critical synthesis of literature on the Promoting Action on Research Implementation in Health Services (PARIHS) framework. Implement Sci 2010,5:82. DOI: 10.1186/1748-5908-5-82
- 38. Howell D, Mayo S, Currie S et al. Psychosocial health care needs assessment of adult cancer patients: a consensus-based guideline. Support Care Cancer Published online May 13, 2012. DOI: 10.1007/s00520-012-1468-x.