

Chapter 10:

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Audio-recording cancer consultations for patients and their families—putting evidence into practice

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Introduction to audio-recording cancer consultations

The experience of cancer is one of the most challenging and potentially devastating events that can befall a person. Physical and psychosocial threats abound throughout the disease continuum; from when the presence of cancer is suspected, through the diagnostic period and treatment phase(s), and either into survivorship ~~or~~ to palliation and the final breaths of life. The process of adjustment to cancer involves a myriad of coping responses, many of which involve processing information to inform treatment decisions or the management of symptoms or treatment side-effects. Effective communication between the patient, family, and healthcare professional is pivotal to adequately informing the patient about disease and treatment options, promoting patient participation in medical decision-making, and fostering psychosocial adjustment in the patient. It is through patient–professional discourse that patients come to better understand the specific nature of their disease, as well as their unique treatment needs. These professional consultations are the vehicle by which patients can participate knowledgeably in the treatment decision-making process; yet patients commonly enter the consultation room in a state of elevated anxiety and leave with a weak recollection of information provided. For this reason, health professionals frequently encourage patients to ask a family member to accompany them to important consultations. Family members

can be a source of emotional support and provide assistance with decision-making but they, like patients, have poor memories of consultation content. If the information that is imparted during any given consultation is essential for making informed decisions, then interventions are needed to enhance information comprehension and retention, thereby fostering patient and family participation in medical care decisions. One such intervention that holds empirical promise is furnishing patients and their families with audio-recordings of important consultations.

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The purpose of this chapter is threefold:

1. to briefly review the empirical literature on the value of consultation audio-recordings for patients and families;
2. to conduct a theory-driven examination of the factors that limit practice uptake of this intervention; and
3. to provide practical suggestions for how these factors might best be addressed to enhance clinical uptake of consultation audio-recording-use.

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Review of empirical evidence

Patients must understand their disease and treatment options sufficiently to be effective treatment consumers. While not all patients may express a wish to have greater control over the medical decisions that affect their well-being, research evidence suggests it is in their best interest to do so: Patients who adopt a passive role in decision-making have overall poorer adjustment to their cancer than patients who are actively involved (Hack *et al.*, 2006). Many factors are likely to contribute to this passive role: lack of disease knowledge, lack of general education, lack of ability to respond assertively, and fears of death, which all serve to silence patients during consultations. If the values we

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espouse for communication during oncology consultations include patient–professional collaboration, fully informed patient consumers, and greater decision-making control by patients, then efforts are needed to enhance the processes involved in conveying information to patients.

One intervention that holds empirical promise in addressing the unmet needs and concerns of newly diagnosed and follow-up cancer patients is ~~the~~ consultation audio-recording (Pitkethly ~~et al.~~*et al.*, 2008). The evidence supports the conclusion that audio-recordings of oncology consultations provide valuable benefits to patients. These recordings allow for memories to be refreshed; for the learning of information not recalled from the consultation; for a clearer understanding of one’s cancer treatment; for greater confidence that critical aspects of the disease and treatment have been discussed; and for greater information recall. Consultation recordings provide patients with a means by which to initiate disease and treatment discussions with family members and helps patients assume a significantly more active role in subsequent consultations. Consultation recordings are well received by the majority of cancer patients. In a recent qualitative analysis of patient interviews, patients reported four primary benefits: anxiety reduction; enhanced retention of information; better informed decision-making; and improved communication with family members (Hack ~~et al.~~*et al.*, 2013).

From the research conducted in this area, we can conclude that consultation recordings improve information recall, reduce anxiety, enhance patient satisfaction with communication, and increase patients’ perceptions that essential aspects of their disease and treatment have been addressed during the consultation. The Cochrane Collaborative Group, in its revised systematic review of the consultation recording research literature,

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concluded that ~~“~~the provision of recordings or summaries of key consultations may benefit most adults with cancer. Although more research is needed to improve our understanding of these interventions, most patients find them very useful. Practitioners should consider offering people tape recordings or written summaries of their consultations~~”~~ (Pitkethly ~~et al.~~ *et al.* 2008, p. 1).

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Theoretical considerations

Despite the empirical evidence supporting the provision of consultation recordings in oncology, the uptake of this intervention into practice has been limited. Knowledge translation theories are useful for understanding why the uptake of promising psychosocial interventions is slower than might be expected, given the strong evidence base. These theories suggest that successful wide ~~spread-scale~~ dissemination requires that obstacles which impede uptake be identified and addressed.

While translation of healthcare knowledge is not successful if the knowledge itself is not relevant, unbiased, and based on all available evidence (Boissel ~~et al.~~ *et al.* 2004), translation is also not possible if the knowledge is not adequately transferred. Knowledge transfer is a component of knowledge translation and refers to the technical process that brings information from the empirical literature to practitioners and caregivers. One of the more common findings from health service research is a failure to routinely translate research findings into daily clinical practice (Grimshaw ~~et al.~~ *et al.* 2004). Simple diffusion and passive dissemination of research findings are largely ineffective at changing practice (Chilvers ~~et al.~~ *et al.* 2002). Some practitioners have difficulty finding, assessing, interpreting, and applying the best evidence (Ely ~~et al.~~ *et al.* 2002; Haynes ~~and~~ *&* Haines, 1998; Pearcey, 1995).

One useful theoretical framework to consider when moving empirically promising communication interventions into mainstream clinical practice is the Promoting Action on Research Implementation in Health Services (PARIHS) Framework (Rycroft-Malone, 2004). The PARIHS framework was conceived by colleagues at the Royal College of Nursing (RCN) Institute in the United Kingdom (Harvey ~~et al~~ *et al.* 2002; Kitson ~~et al~~ *et al.* 1998; McCormack ~~et al~~ *et al.* 2002). They posited that knowledge translation can be explained as a function of the relationship between *evidence* (research, clinical experience, and patient preferences), *context* (culture, leadership, and measurement), and *facilitation* (characteristics, role, and style), with these three elements having a dynamic, simultaneous relationship. The most successful implementation occurs when evidence is robust, the context is receptive to change, and the change process is appropriately facilitated (Kitson ~~et al~~ *et al.* 1998). Without a thorough understanding of the contextual factors that serve to stimulate, support, and reinforce the use of ~~audio recordings~~ audio recordings in oncology, this practice is likely to fail. Given the ~~interrelationship-~~ relationship between evidentiary, contextual, and facilitative factors, it is necessary to examine the complexities of these relationships if audio-recording practice is to be successfully adopted.

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Evidence

Evidence (Rycroft-Malone ~~et al~~ *et al.* 2004) comes from four sources: research, clinical experience, patients, and the local context/environment. Research organizations have traditionally focused on the generation of research evidence demonstrating effectiveness. This is certainly the case for consultation ~~audio recordings~~ audio recordings. Systematic reviews of the empirical literature, such as the Cochrane review of consultation recording

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studies, quicken the rate at which research findings are understood but provide no promise of integration of clinical practice and research findings. This lack of integration may be a function of well-intentioned clinicians trying their best to work in healthcare settings that are busy and complex (Grimshaw *et al.* 2004). When research is successfully translated, this is often after considerable, unacceptable delay (Pearcey, 1995). Rycroft-Malone (2004) calls for an enhanced understanding of the ways in which research evidence interacts with the evidence of clinical practice, the needs and experiences of patients, and the feedback mechanisms of the social and professional networks that comprise the organizational history and culture. By this definition, evidence in support of consultation audio-recording use is broader than published empirical reports of effectiveness, and efforts to transfer consultation audio-recording knowledge become multi-faceted. Little research, for example, has been conducted to understand the experiences and perceptions of oncologists with respect to consultation audio-recording (Figure 10.1).

Insert Figure 10.1 here

While the empirical literature unequivocally demonstrates benefits for patients associated with having a consultation audio-recording, we do not understand the mechanism(s) by which these benefits are derived. The benefit of recall is clearly associated with listening to the recorded consultation. However, it is not known why and how anxiety is reduced, and why patients are satisfied with the intervention. While it may be inferentially argued that more informed patients are consequently more satisfied, little is known about how patients derive benefit from listening to the audio-recording. For example, what information on the audio-recording is most helpful to patients and families? Does the audio-recording inform treatment decision-making? Is there a more

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intangible benefit to having a recording, such as being more positively disposed toward~~s~~ the oncologist, or feeling more ~~“connected”~~ to family members who listen to the audio-recording? If the factors that contribute to the derivation of patient benefit can be systematically identified, then we can better facilitate the uptake of consultation audio-recording use to maximize patient benefit.

Context

Context is characterized as having three themes: culture, leadership, and measurement or evaluation (McCormack ~~et al~~ *et al.* 2002). The culture of a practice context needs to be understood if meaningful and lasting change is to be achieved. By examining the context of consultation audio-recording use in cancer cent~~res~~, the cultural, leadership, and measurement factors that shape the uptake of consultation_~~r~~-recording use can be identified. With respect to organizational climate, few cancer cent~~res~~ have established policies governing consultation_~~r~~-recording use.

Although many important barriers to knowledge translation exist at the level of the healthcare professional (Rycroft-Malone, 2004), there are structural and organizational barriers to integrating research evidence into practice which operate at levels beyond the control of the individual clinician. Structural barriers are those environmental factors that impede knowledge translation. In oncology settings, a frequently occurring structural barrier to adoption of psychosocial interventions is a lack of financial resources; consultation recording equipment must be purchased and staff resources may be necessary to enable implementation. A potential organizational barrier is the absence of institutional or collegial peer pressures to use this intervention. The likelihood of uptake of consultation recordings may be enhanced through the support of

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‘champions’ at all levels of the organization, including senior administrators and clinical staff.

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Facilitation

Facilitation (Harvey ~~et al~~ *et al.* 2002) refers to the process of enabling the implementation of evidence into practice; ‘enabling others’ rather than ‘doing for others’. In the context of knowledge translation, ‘enabling’ may have a greater impact than ‘doing’ because practitioners need time to consider and assimilate research findings. If oncologists tend to only use consultation recordings within the context of a research study, then we may be merely obtaining time-limited ‘buy-in’ or ‘doing for others’ or, more precisely, ‘guiding the hands of others’ rather than enabling oncologists to become self-motivated and self-directed in using this intervention.

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Motivation is a critical behaviour change factor that underlies the use of consultation ~~audio recordings~~ audio recordings by oncology professionals. Lack of exposure to the benefits of consultation ~~audio recordings~~ audio recordings may result in clinicians who believe there is a lack of positive, consensus evidence for their use. Where unfounded negative attitudes towards this intervention exist, such as the risk of litigation, these attitudes may serve as strong barriers for implementation. For this reason, efforts to educate oncologists about the benefits of consultation ~~audio recordings~~ audio recordings may be a fundamental component of oncologist acceptance of the intervention and successful implementation. Continued positive reinforcement will sustain positive oncologist attitudes towards consultation audio-recording use.

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Social barriers to knowledge translation are often critical when groups of individuals are encouraged to adopt an intervention. The successful uptake of

consultation audio-recording use relies on a substantial proportion or “critical mass” of oncologists integrating the intervention into clinical practice. Social network theory is useful for examining ideas about the best ways to overcome the social barriers that impede the transfer and uptake of consultation audio-recording use. Social network theory predicts that an intervention is more likely to be adopted, the greater the number of interconnected individuals who use it, and if an integrated social structure can be established to support adoption (West *et al.* 1999). By deliberate rewiring of the interactions between oncologists, nurses, patients, and families through the provision and explanation of evidence, support in the use of consultation ~~audio recordings~~ audio recordings, and the application of policies guiding consultation audio-recording use within the organization, we may potentially increase the density of the cancer patient–professional social network (Buchanan, 2002). West *et al.* (1999) argued that a dense social network has advantages for knowledge translation: “The multiplicity of ties gives members the opportunity to persuade, cajole, and monitor the performance of others” (p. 635). An objective for promoting consultation audio-recording use is to utilize the professional hierarchy of oncology practice to “cascade” consultation audio-recording evidence, increasing the density of the social context of consultation audio-recording use, and thereby facilitating uptake into clinical practice. Social network theory also suggests that those individuals with the most influence or power in using the intervention and promoting its use among others should be identified as change agents. Among oncologists, disease site leaders might be identified and approached, particularly if these oncologists can instruct other oncologists and nurse specialists within their disease specialty to adopt consultation audio-recording use.

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An implicit assumption in much of the writing on social barriers is that most knowledge translation activities should be directed towards the health professional. There are proportionately fewer studies that identify selected patient groups as the target for change. This is perhaps not surprising given that the goal of most knowledge-transfer activities is to change the practice style of treating clinicians' practice style. However, there may be evidence that is sufficiently compelling to cause a significant proportion of cancer patients or the general public to mobilize in an effort to change clinical practice. The significance of cancer patients and their advocacy organizations in promoting interventions that may enhance their psychosocial well-being should not be underestimated. Indeed, advances in computer technology have made it easier for cancer patients to audio-record consultations on their mobile cellular phones, and this key technological development is associated with an increase in the proportion of patients who are recording their consultations with or without the expressed permission of health professionals. Many local, legal jurisdictions allow for patients to record their consultations as "co-owners" of their consultation. In these jurisdictions, cancer patient advocacy groups can play a significant role in encouraging cancer centres to audio-record pivotal consultations. Studies are needed to identify and address the role of cancer patients and their advocacy groups as change agents in the consultation audio-recording transfer process.

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Case study: ~~a~~Assessment of receptiveness to consultation audio-recordings audio recordings

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By way of example, we will use respective consultation recording research programmes in Australia, Canada, and the United Kingdom to illustrate the

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application of the PARIHS framework ~~forte~~ enhancing the transfer and uptake of the consultation audio-recording intervention. Consistent with the functions of knowledge ‘~~brokering~~’, if the translation goal is to see more clinicians using a new intervention, then the probability of success will be enhanced if clinicians are included as co-investigators of the research and if they are involved in an advisory capacity throughout the research process (Lomas, 2007). We sought out oncologists who have used consultation ~~audio recordings~~ audio recordings in clinical practice and who hold senior positions within their respective cancer disease sites. We identified health professionals who are well suited by their practice history and power status to serve as local champions for the use of consultation ~~audio recordings~~ audio recordings, and invited them to join the research team as co-investigators.

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In the development phase of a recent project, the principal investigator travelled ~~ed~~ to each participating centre ~~re~~ to interview oncologists, nurses, ~~and and~~ other front-line staff about consultation recording use, asking them to share their opinions on the relative merits, perceived barriers, and facilitative facets of this intervention. Given that an understanding and acceptance of the best empirical evidence in support of consultation recording use is fundamental to successful uptake, the principal investigator arrived at each interview with evidence in hand: a copy of the Cochrane Collaboration systematic review of consultation recording use (Pikethly ~~et al~~ *et al.* 2008), copies of publications of the consultation recording studies conducted by the research team, and a copy of a recent newspaper article speaking to the value of consultation ~~audio recordings~~ audio recordings for newly diagnosed oncology patients. These materials were offered to the interviewee, if appropriate. Nearing the end of each interview, the interviewer explained that a

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detailed proposal to examine the transfer and uptake of the consultation audio-recording intervention would be developed only if there was sufficient interest among the oncologists and nurses being interviewed. It was encouraging that all of the interviewees supported the idea and expressed their willingness to participate. The interview transcripts showed that the oncologists and nurses were able to identify several barriers and contextual factors that inhibited consultation audio-recording use at their centre.

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The respondents frequently differed both in their assessment of the benefits to patients of receiving a consultation audio-recording, and in their identification of factors that were critical to enhancing the uptake of consultation audio-recording use. These and other considerations of evidence, context, and facilitation are presented in **Box 10.1** as guidelines for use when designing a research study to examine the consultation audio-recording intervention within a knowledge translation framework.

Insert Box 10.1 here

Looking forward

For oncology professionals who want to integrate audio-recording of key consultations into their practice, we offer the following basic suggestions:

- Secure the availability of audio-recording equipment in all clinic rooms.
- Assign responsibility for recording the consultation to a specific staff member.
- Introduce to patients the topic of consultation recordings. For example:
“Today I will provide you with important information about your disease and treatment that you may want to remember. To make it easier to remember what we talk about, many patients find it helpful to receive an

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audio-recording of the discussion. I would like to offer you an audio-recording of our discussion. You can then take the recording home with you to listen to on your own or with family and friends.²²

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- Obtain, from the patient, informed written consent to be recorded. Consider including a disclaimer statement to protect the recorded professional from medico-legal liability associated with patient use of the recording.
- As an expression of respect for patient privacy, do not record the physical examination portion of the consultation.
- Retain a copy of the recorded consultation within the oncology department.

While recent reviews provide a compelling, evidence-based case for consultation audio-recording use, additional studies are warranted. Studies are needed to examine the process of implementing consultation audio-recording use into oncology practice. We need to address the factors that impede the transfer and uptake of consultation audio-recording use and test ideas about the best ways to transfer intervention knowledge and support intervention uptake. These studies should be guided by theoretical frameworks relevant to knowledge transfer and uptake, such as the PARIHS Framework and Social Network Theory. The field of knowledge translation is growing rapidly, and new theoretical frameworks are being developed, while existing ones are being adapted for use as knowledge translation frameworks. Further research is needed to examine the suitability or heuristic value of these theories to examinations of the transfer and uptake of the consultation audio-recording intervention.

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While the empirical evidence-base demonstrates the value of furnishing patients with consultation ~~audio recordings~~ audio recordings, greater attention needs to be paid to the benefits that family members receive from listening to the audio-recording, the manner by which patients and families derive benefit and value, and the benefits to clinicians of having their consultations recorded for use by patients and family members. We need to identify and describe any subgroups of patients and families for whom consultation ~~audio recordings~~ audio recordings are most beneficial. Last, we need to document the types of consultations that are most valuable to patients and families. While most of the empirical literature has focused on the initial treatment consultation, there may be unique benefits associated with providing patients with ~~audio recordings~~ audio recordings of any consultations in which a change of treatment or care is indicated, such as consultations following disease recurrence or a switch to palliative care.

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Fig. 10.1

PARIHS framework: **k**nowledge translation as interrelationship of evidence, context, and **and** facilitation.

Box 10.1

Evidence, context, and facilitation considerations for consultation audio-recording studies

Knowledge of consultation recording evidence. Are patients, families, and oncology staff aware of the evidence?

Perceived quality of evidence. How do patients, families, and oncology staff rate the quality of the evidence?

Perceived value and benefit. What is the perceived value and benefit of consultation recordings?

Relative value and benefit. How does this intervention compare against other ways of providing information?

Perceived impact of consultation recording on oncologist behaviour. Will oncologist involvement possibly reduce spontaneity during consultation; or improve the quality of communication?

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Leadership. Is there an individual or group to champion the intervention?

Legal concerns. Who owns the recording—the patient, oncologist, or cancer centre?

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Can oncology staff or the cancer care organization be successfully sued for what is said on the recording? Is there a need to consult legal counsel?

Time constraints. Is there sufficient time for oncology staff to record consultations?

Privacy. What protective measures need to be taken to minimize patient risk?

Data storage. Where and how will recordings be stored, if at all?

Lack of infrastructure. Is there a sufficient number of recording devices and associated materials available in clinic?

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Intervention cost. What is the cost to sustain the intervention?

Resource cost. What is the staff cost to implement *and* sustain the intervention?

Motivation. Will oncology staff be compensated or reinforced for participating? Will oncology staff performance be evaluated?

Technology type. What options are available for recording the consultation—USB key (memory stick)? ~~Mobile Cellular~~ phone? Web address? Should the digital recording be converted to a text file? Should one type of technology be used for all patients or should options be available?

Availability of technology. Are all patients able to access the chosen technology? Do older patients have access to ~~mobile cellular~~ phones or computers? Is there a need to accommodate different computer operating systems?

Delivery mode. Will the patient or cancer centre ~~re~~ supply the recording equipment? Will the intervention be patient or provider driven? Who will press the ~~“record”~~ button? How will the recording be accessed by patients and family members?

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Staff support. Who will identify eligible patients—clerks, nurses?

Message. Will the entire consultation be recorded or only a portion thereof? Will the medical history be recorded? Will the physical examination be recorded? Which ~~healthcare care~~ professionals will be recorded?