

Evidence-Based Series #19-2- Education and Information 2011

A Quality Initiative of the Program in Evidence-based Care (PEBC), Cancer Care Ontario (CCO)

Provider-Patient Communication

G. Rodin, J.A. Mackay, C. Zimmerman, C. Mayer, D. Howell, M. Katz, J. Sussman, S. McNair, and M. Brouwers

Report Date: March 17, 2008

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Section 1: RecommendationsSection 2: Evidentiary BaseSection 3: EBS Development Methods and External Review Process

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Evidence-Based Series #19-2: Section 1

Provider-Patient Communication: A Report of Evidence-Based Recommendations to Guide Practice in Cancer

G. Rodin, J.A. Mackay, C. Zimmerman, C. Mayer, D. Howell, M. Katz, J. Sussman, S. McNair, and M. Brouwers

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QUESTION

What aspects of provider-patient communication, at critical points of care, have an impact on clinical outcomes of cancer patients?

- The critical points of care of interest are diagnosis, recurrence, identification of metastases, and progressive disease.
- Outcomes of interest include psychosocial or emotional distress in patients (e.g., anxiety, depression), patient satisfaction, patient quality of life, and patient recall or understanding of information communicated by providers.
- The components of provider-patient communication that are the focus of this report are communication styles and approach. The clinical content and strategies related to specific clinical issues in each of the critical points of care are not the focus of this report.

TARGET AUDIENCE

Oncology health care professionals interacting with cancer patients during critical points of care.

RECOMMENDATIONS

The Program in Evidence-based Care's (PEBC) Provider-Patient Communications Working Group (see Section 2: Appendix 1) has selected the Australian National Breast Cancer Centre and National Cancer Control Initiative (NBCC-NCCI), *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer* (available from http://www.nhmrc.gov.au/) as a framework for this area of practice. The recommendations below reflect the integration of the NBCC-NCCI recommendations, an updated systematic review of the research evidence since the release of these guidelines, and consensus by the PEBC Provider-Patient Communications Working Group.

Health care providers in Ontario should be aware of the current legislation (Regulated Health Professions Act, 1991; current version available from <u>http://www.e-laws.gov.on.ca</u>) regarding communication at critical points in care.

General Interaction Skills Evidence-based Rationale (NBCC-NCCI Evidence Grading Levels I and II)

- The way in which a clinician and treatment team relates to and communicates with a patient can benefit the patient and their family by improving aspects of psychosocial adjustment, decision making, treatment compliance, and satisfaction with care.
- Aspects of communication that are important include empathic listening and creating an environment where a patient is free to express feelings and ask questions.
- A patient's understanding, recall and/or satisfaction with care may increase when techniques are used to reinforce or record what has been communicated These techniques may include taping of consultations, providing general information tapes, sending summary letters as a follow-up to consult, and/or including a support person in the clinical visit.

Recommended Approach: General Interaction Skills

The following skills are considered important in any consultations or interactions with persons with cancer at any stage of the disease:

Supportive communication

- Identify and adhere to the person's stated preferences in the approach to information exchange and decision making.
- Allow patients the opportunity to have a support person with them during the consultation and inform them about this possibility in advance of the visit.
- Show regard and concern for the person by using verbal and non-verbal behaviour that is appropriate for the age, cultural background, and preferences of the patient.
- Use active empathic listening, facilitating the person's responses.
- Allow the person to express any concerns, fears, anxieties or anger in a manner that aligns with his or her communication preferences at the time (e.g., talking, crying).
- Discuss embarrassing or disturbing topics in a manner that aligns with the person's communication preferences.
- Offer patients access to psychosocial support that is sensitive to their unique needs.

Communicating in understandable language

- Assess the person's understanding before providing additional information.
- Explain difficult terms and avoid medical jargon.
- Be culturally sensitive.
- When possible, it is preferable to use professional translation services rather than hospital staff, volunteers or family members.

Strategies to aid recall and understanding

- Allow the opportunity for patients to ask questions and seek understanding.
- Make use of simple diagrams and pictures where appropriate.
- Repeat and summarise important information.
- If appropriate, reinforce important information by using one or more of the following aids:
 - writing down relevant information.
 - taping the consultation as needed and if wanted.
 - sending a summary letter as follow-up to the patient.

Recommended Approach: Common Skills across Critical Points of Care

In addition to the general interaction skills above, the following steps are recommended when telling a person they have cancer, a recurrence, or metastases.

Prior to discussing diagnosis, recurrence or metastases

- Ensure that the news is given in person, in a quiet, private place and allow enough uninterrupted time. When this is not possible, ensure that the person is well supported before disclosure is made.
- Encourage the presence of a second relevant person, if appropriate.
- Arrange the provision of other methods to convey additional information, including written materials, video tapes, or tapes of consultations based on patient or family request.

When providing information on diagnosis, recurrence or metastases

- Assess the person's understanding of their condition and their personal preference for information. For example, ask, "Tell me, in your own words, your understanding of your condition?"
- Briefly explain the process by which the diagnosis was reached.
- Provide information simply and honestly, using lay terms rather than euphemisms.
- Avoid giving the message that 'nothing can be done'.
- Clearly indicate that while you may make recommendations about the range of acceptable care options, you are willing to be involved in the ongoing care of the patients (if required) no matter what they decide in response to your recommendations and that their consent to care options is required in order to proceed with them.

Emotional and supportive role

- Allow the opportunity for the person to express their feelings, such as talking about concerns, fears, anger or anxieties, and to cry freely, and respond to their feelings empathically.
- Address disturbing or embarrassing topics in a manner that aligns with the person's preferences.

Concluding the discussion

- Summarise the main points of the consultation and assess the person's understanding.
- Ask if there is anything more the person would like to discuss.
- Allow the opportunity to assist with telling others any difficult news.
- Indicate your availability to address any questions or concerns and arrange a further appointment to review the situation within a stated time period (e.g., within 24 hours to two weeks).
- Assess the person's understanding of their prognosis.

After discussing a diagnosis, recurrence or metastases

- Document any information given to the person and family members.
- Let others, particularly the individual's general practitioner, know in a timely manner, the extent of information given and your perception of the person's understanding.
- Ensure that there is a provider with whom the person is able to debrief after the interaction.

How to Discuss Prognosis Evidence-based Rationale (NBCC-NCCI Evidence Grading Level II)

• The way in which a prognosis is communicated (e.g., the use of words or numbers, the discussion of survival or death as the outcome) and the time taken to explain information both can influence patients' emotional reactions and decisions about treatment.

Recommended Approach

The following steps, in conjunction with the general interaction skills, are recommended for discussing prognosis with individuals with cancer:

Offering prognostic information

- Ask first if the person wants to be given information about prognosis, (e.g., "I can tell you what happens to most people in your situation. Would you like me to do that?") and what they currently understand and expect.
- Offer prognostic information as part of treatment decision making prior to commencing treatment.

Aspects of prognosis to discuss

- Adhere to the person's stated preference for information about prognosis. If or when desired, the following can be provided:
 - staging details and their implications for prognosis.
 - chances of being cured or that cancer will never return.
 - likely benefits and risks of treatment.
 - average and longest survival times, emphasizing a range rather than a single time point.

How to discuss prognosis

- Preface any prognostic estimate with its limitations:
 - explain that you cannot predict with certainty how this person will respond to the illness and its treatment.
 - provide an initial prognosis, based on available information, and explain how this may be revised by additional information. Suggest a time frame for when additional prognostic information is likely to be available.
- Use mixed framing: give chances of cure first, and then chances of relapse.
- As needed, present information in a variety of media: words, statistics, graphs, and:
 - combine verbal estimates, e.g. 'small chance' with numerical estimates.
 - provide verbal explanations of survival graphs.
- When explaining relative risk reduction, provide several examples of the calculations, and:
 - only use statistical terminology, such as median, hazard ratio, or relative risk, if a person is familiar with these concepts.

Concluding the discussion

- Provide hope-giving aspects of the information, including ongoing care the person will receive.
- Provide necessary information for the person to plan for the future.
- Assess the patients understanding of their prognosis.

How to Discuss Treatment Options Evidence-based Rationale (NBCC-NCCI Evidence Grading Levels I and II)

- Appropriate and detailed information promotes understanding and increases the psychological well-being of people with cancer.
- Patients' recall of information increases when they are provided with individualised information.
- Providing a question prompt sheet to cancer patients during an initial consultation may promote patient questions and reduces anxiety, improves recall, and shortens the consultation.

Recommended Approach for Discussing Treatment

The following steps, in conjunction with the general interaction skills above, are recommended for discussing treatment options.

Information about treatment

- Explain to the person, using lay terms, what treatment options are available (including no treatment) and ask how much detail they would like to receive about each option.
- Tailor the information to the person's needs and preferences for information content and detail, and include a discussion of the expected outcomes and major side effects of each treatment option.
- Acknowledge the uncertainty of any treatment achieving its aim; explain the pros and cons of each option and summarise the treatment options.
- Offer a variety of media to provide information about treatment options: written information, decision aids, video tapes, or tapes of consultations.
- Ask the person if they have any questions regarding alternative and complementary therapies.
- Ask the person to talk about the concerns they have regarding different options.

Making decisions about treatment

- Explore at an early stage how the patient would like to be involved in decision making and adhere to their wishes.
- Be aware that the person's preferences may change over time and regularly check the level of involvement they would like.
- Ask the patient about their values and life situation in relation to the treatment options.
- Use inclusive language such as we and our.
- Make it explicit that there are choices to be made and that the patient should be involved in these choices.
- If the person is unaccompanied, ask whether they would like to discuss treatment options with family or friends, and tell the person that there is an opportunity for these individuals to be involved in treatment decisions, if desired.
- Assure the person that there is enough time to consider the treatment options, and offer to arrange a return visit for them when they have made a decision.

Emotional and supportive role

- Consider the specific needs related to gender, age, and culture.
- Allow the opportunity for the person to discuss and express their feelings (e.g., talking about concerns, fears, anger, hopes, or anxieties; crying freely).
- Acknowledge individual differences in emotional impact.

• Make your own recommendations about the range of acceptable treatments, but also express your willingness to be involved in the patient's ongoing care of (if required), no matter what they decide in response to your recommendations.

Concluding the discussion

• Offer assistance in telling others any difficult news about treatment choices.

After discussing a diagnosis, recurrence or metastases

- Document information given to the person and family members.
- Let others know the extent of information given and your perception of the person's understanding, particularly their general practitioner.

Recommended Approach for Discussing Disease Progression

The following steps, in conjunction with the general interaction skills described above, are recommended to prepare patients for progression of disease.

- Provide information openly and honestly about changes in the cancer, treatment efficacy, and when requested, about prognosis.
- Offer the opportunity for the person to voice concerns and goals before discussing specific clinical decisions.
- Ask open-ended questions, such as:
 - What concerns you most about your illness?
 - What has been most difficult about this illness for you?
 - What are your hopes and expectations and fears about the future?
 - As you think about the future, what is the most important to you?
 - Is faith (religion, spirituality) important to you in this illness?
 - Would you like to explore these matters with someone?
- When concerns have been discussed, provide reassurance, when possible, about issues such as symptom management, and the availability of expert palliative care.
- Offer the opportunity to fully explore the patient's understanding of palliative care and emphasize its role throughout illness.
- Clearly assure the patient that they will receive optimal care and will not be abandoned.

Planning care

- Assess the patient's ability and willingness to be involved in decision making, and identify a substitute decision maker, if necessary. Check with the patient and their family members about the amount and type of information they desire.
- Discuss the usual need for greater family involvement, because the patient's awareness and communication capacity decrease with disease progression.
- Keep the patient, and, when permission has been obtained, the family, informed about issues that are most important to them, such as the likely course of the disease, symptom management, and service availability.
- Ask about the person's understanding of their disease status, including their current needs and priorities.
- Discuss a plan for future management and monitoring, including an understanding of shortterm and medium-term outcome goals. Review plans and wishes for advanced care with patients and/or family.

Physical issues

- Introduce the notion of active treatment of symptoms and the importance of its role in ongoing care.
- Discuss and clarify the current targets of symptom management and actively enquire about the person's symptoms.
- Provide the person and their family with information about specific measures available for symptom relief.

Psychological issues

- Offer the person the opportunity to discuss how they and their family are coping with the disease and how others' reactions to the disease are affecting the person's well-being.
- Where appropriate, make specific arrangements for counselling and support/information to be available for the person and their family.

Social issues

- Allow the opportunity for open communication and the expression of feelings and fears in relationships and for discussions with family and friends related to dying and death.
- Address practical issues such as planning for care and support at home, making a will, designating power of attorney, and applying to palliative care units, in a timely and sensitive manner.

How to Prepare Patients for Medical Procedures Evidence-based Rationale (NBCC-NCCI Evidence Grading Levels I and II)

- Providing patients with information about the procedure they are about to undergo reduces emotional distress and improves psychological and physical recovery.
- Practical details about the procedure (procedural information), such as a booklet, videotape, or CD, decrease anxiety and psychological distress. This information can be provided by a clinician or other health professional such as a specialist nurse.
- Information about what they are likely to experience before, during, and after a procedure (sensory information) decreases anxiety.
- Psychosocial support before undergoing surgery reduces psychological distress.

Recommended Approach for Preparation for Medical Procedures

The following steps, in conjunction with the general interaction skills above, are recommended to adequately prepare a patient for a medical procedure:

Before the procedure

- Ask how much detail the patient would like to know about the procedure before explaining it.
- Explain why the procedure is needed and the expected outcome based on stated preferences.
- The information may include:
 - where the procedure might take place, and who will perform it.
 - any tests needed before the procedure.
 - what the patient will need to do before the procedure.
 - what the patient is likely to experience during and after the procedure.
 - how their discomfort will be managed before and after their procedure.
- Allow the opportunity for the person to talk about their concerns such as embarrassment, pain, fear, or death.

During the procedure

- Offer to provide information about what will be done and how it will feel.
- Provide patients with the level of control they feel most comfortable with (e.g., for some, asking them to tell you when they are ready to begin may be appropriate).

After the procedure

• Encourage the patient to state their needs and reframe complaints into requests.

KEY EVIDENCE

The complete evidentiary base for this review included:

- o four evidence-based practice guidelines,
- o eight systematic reviews, and
- o nine randomized-controlled trials.

Although the complete evidentiary base was appraised and used by the PEBC Provider-Patient Communications Working Group to inform their deliberations, the Group decided that the NBCC–NCCI guideline would serve as the foundation for the Ontario recommendations.

Key Findings

- Evidence supports the need to individualize communication style to meet patient preferences.
- Patients vary in their desire for active participation in decision making.
- There is little definitive evidence supporting one specific method compared to another for communicating information (e.g., prognosis).
- The evidence for the benefit of tools (e.g., checklists, question prompts, information pamphlets) and of strategies (e.g., audiotapes) to consolidate patient information or facilitate better communication and greater patient satisfaction is inconsistent; they may be of value for some patients.
- While evidence evaluating the role of decision aids is inconsistent, they may be appropriate for some patients.

RELATED GUIDELINES

PEBC Evidence-based Series reports:

- EBS 16-2 Cancer-related Pain Management
- EBS 19-2 Advanced Care Planning with Cancer Patients
- EBS 20-2 Effective Teaching Strategies and Methods for Patient Education
- EBS Special Report: Establishing Comprehensive Cancer Patient Education Services
- EBS Special Report: Multidisciplinary Cancer Conference Standards

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EVIDENCE-BASED SERIES #19-2

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Evidence-Based Series #19-2: Section 2

Provider-Patient Communication: Evidentiary Base

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QUESTION

What aspects of provider-patient communication, at critical points of care, have an impact on cancer patient outcomes?

- The critical points of care of interest are diagnosis, recurrence, identification of metastases, and progressive disease..
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INTRODUCTION

Psychosocial oncology is increasingly recognised as an important aspect of cancer care (1,2) and emotional distress, which is common in cancer patients, has been proposed as the sixth vital sign (1). Receiving a diagnosis of cancer or learning of the disease recurrence or metastases is an emotionally distressing time for most patients, but the process of communication between providers and patients can have an impact on this outcome (3). A relationship of health care providers with patients, based on mutual trust, respect, and reciprocity and with mutually negotiated goals and expectations can be an important support and buffer of distress for cancer patients. As a part of the Cancer System Quality Index in Ontario, patient satisfaction with outpatient cancer care in 2004-2005 was found to be reasonably high for overall communication (average ratings, 77%) but only moderate for provision of emotional support (50-60%). However, the ratings were not specific to provider-patient interactions (4).

A 1995 systematic review of physician-patient communication and its impact on health outcomes among patients with a broad range of diagnoses included 21 studies, 11 of which were randomized, and four of which included cancer patients (5). The review found that aspects of physician-patient communication that had a positive impact on patient outcomes included the physician providing clear information, expressing empathy and support, exploring the patient's feelings and concerns, encouraging patient questions, being willing to share decision making, providing information programs or packages, and ensuring patient understanding. In addition, patients' ability to express themselves and to obtain information was associated with better functional and physiological status. The patients' family and friends are also frequently involved in the communication with patient family and friends is not specifically addressed here because the provider-patient connection is the focus of this review.

Although the assessment of psychosocial distress is recognized as an important component of the provider-patient interaction, the identification of distress is only meaningful when there are practical options available for dealing with it. Taking steps to minimize the potential for patient distress during the communication process may be an important first step in reducing the overall patient burden of disease. The aim of the current systematic review is to identify aspects or methods of provider-patient cancer-related communication that may positively or negatively impact on patient outcomes associated with distress and to explore ways in which providers can incorporate aspects of effective communication in their everyday consultations with patients.

METHODS

This systematic review was developed by Cancer Care Ontario's Program in Evidence-Based Care (PEBC), using the methods of the Practice Guidelines Development Cycle (7). A seven-member panel of experts, PEBC Provider-Patient Communications Working Group (see Appendix 1), was convened to develop the evidence-based series report recommendations and approve the final report. The Panel was comprised of palliative care physicians, psychiatrists, nurses, oncologists, a social worker, and methodologists. Although there were no patients in the panel that developed this guideline, the evidentiary base was defined by studies that investigated the patient experience and reported on patient-centred outcomes.

This systematic review is a convenient and up-to-date source of the best available evidence on provider-patient communication relating to critical points of care (cancer diagnosis, recurrence, or metastases, or end of life) and its impact on patient outcomes. This evidence was used by the PEBC Provider-Patient Communications Working Group as a basis for discussion and consensus-building in the development of provider-patient communication recommendations. The systematic review and companion standards are intended to promote evidence-based practice in Ontario, Canada. The PEBC is editorially independent of the Ontario Ministry of Health and Long-Term Care.

Literature Search Strategy

The following electronic databases were searched for relevant evidence: MEDLINE and HealthSTAR (1966–March 2007), PsycINFO (1967–March 2007), EMBASE (1980–week 10, 2007), CINAHL (1982–March 2007), and the Cochrane Database of Systematic Reviews and Clinical Trials Register (2007, Issue 1). The search terms used by intervention, disease type, and publication type are provided in Appendix 2. The reference lists of relevant reports and recent reviews were also searched for additional evidence.

Searches for current guidelines and standards related to provider-patient communication and psychosocial distress included the Web sites for the U.K. National institute for clinical excellence (NICE, <u>http://www.nice.org.uk</u>), the Canadian Medical Association (CMA) Infobase (<u>http://www.mdm.ca/cpgsnew/cpgs/index.asp</u>), and the U.S. National Guidelines Clearinghouse (NGC, <u>http://www.guideline.gov</u>), all searched July 19-24, 2006. The Web sites of the following psychosocial oncology societies were searched on November 28, 2006: Canadian Association of Psychosocial Oncology (<u>http://www.capo.ca/eng/index.asp</u>), British Psychosocial Oncology Society (<u>http://www.bpos.org/</u>), American Psychosocial Oncology Society (<u>http://www.ipos-society.org/</u>), International Psycho-Oncology Society (<u>http://www.ipos-society.org/</u>), and European Society of Psychosocial Oncology (<u>http://www.efpos.org/</u>).

Study Selection Criteria

Eligible articles met both the following criteria:

- focused on the interaction between adult cancer patients and their health care providers during discussions of disease diagnosis, recurrence, metastases, or end of life and,
- reported patient outcomes in relation to the provider-patient interaction, including the use of empirical measures of psychosocial or emotional distress (e.g., anxiety, depression), satisfaction, QOL, or recall or understanding of the information communicated,

and were one of the following publication types:

- evidence-based practice guidelines, systematic reviews, or meta-analyses that included a clear indication that the literature review and selection was systematic (guidelines specified that a literature search was conducted and that the recommendations or conclusions related to appropriate aspects or forms of provider-patient communication), or
- randomized trials that compared different aspects or forms of provider-patient communication with each other or with a standard method of communication.

Non-comparative, prospective studies evaluating the outcomes of interest in response to provider-patient communication strategies were also considered when only limited evidence was available from comparative studies. Studies evaluating provider communication training programs; communication relating to clinical trial participation, disease prevention, screening, or testing; and publications in a language other than English were not eligible for inclusion in the systematic review. Letters, editorials, and commentaries were also excluded as were systematic reviews and meta-analyses published before 1996 and practice guidelines published before 2001. Organizations that publish or index guidelines typically do not consider guidelines more than five years old to be current; therefore, setting a six-year limit for guideline inclusion was considered reasonable. Although the 10-year cut-off date used for selection of systematic reviews is more arbitrary, recent high-quality systematic reviews were considered to be the most relevant as a potential evidence base for the development of recommendations or standards.

RESULTS

Literature Search Results

The reports that met the selection criteria for this systematic review are shown in Table 1. Because two comprehensive guidelines on supportive or psychosocial care for patients with cancer that addressed provider-patient interactions were identified (8-11), a post hoc decision was made to exclude disease-specific clinical practice guidelines that commented on providerpatient communication but focused on the overall management of the disease. One diseasespecific guideline that addressed end-of-life care requirements for lung cancer, rather than general disease management, was included (12). No relevant meta-analyses were identified and the search of the Web sites of psychosocial oncology associations did not locate any guidelines or standards relating to provider-patient communication.

Report type	Number of reports	References	Relevant tables
Practice guidelines	4	(8-13)	Table 2
Systematic reviews	8	(14-21)	Table 3
Randomized trials	9	(22-30)	Table 4, Table 5

Table 1. Reports included in this systematic review.

Outcomes

Quality Assessment

Practice Guidelines

Four relevant evidence-based practice guidelines that addressed some aspects of providerpatient communication were identified and are summarized in Table 2 (8-13). The quality of the guidelines were independently assessed by two raters using the Appraisal of Guidelines Research and Evaluation (AGREE) instrument, which allows for the evaluation of guidelines over six domains: scope and purpose, stakeholder involvement, rigour of development, clarity and presentation, applicability, and editorial independence (31). All the guidelines included noncancer research in their evidence review. The two guidelines that provided limited information on the guideline development process or methodological rigour are not discussed in detail (12,13).

Systematic Reviews

Eight systematic reviews met the eligibility criteria and are summarized in Table 3 (14-21). Most of the reviews focused on provider-patient communication in a range of circumstances, although two primarily included studies of initial oncology consults (20,21), which include diagnostic consults or treatment-related consultations at varying stages of disease. One focused on newly diagnosed patients (17), and one evaluated interventions in patients with recurrent or metastatic disease (19). All reviews included reasonably comprehensive literature searches, and most provided clear literature selection criteria (15,17-21), although the methods for literature selection that may reduce bias (e.g., independent or duplicate review) were indicated in only three reviews (18-20). Most reviews evaluated the validity of the included studies (15,18-21) and provided clear evidence to support their conclusions (15,16,18,20,21). Only one of the reviews conducted a quantitative synthesis of the evidence (17).

Randomized Trials

Nine eligible randomized trials not included in the systematic reviews identified above are described in Table 4 (22-30). The trials were of modest (25,27) or low quality (22-24,26,28-30). Blinding was not possible in most trials because of the nature of the interventions and the focus on self-report outcomes; however, two trials that analyzed consult tapes blinded the tape coders (25,28), and one trial blinded participants to the study purpose but not the intervention (22).

			Recommendations									
Author, year, country	Search sources / dates	Evidence included	General	Senior provider communicates significant news	Patient support services	Adequate consult environment	Diversity awareness	Solicit patient preferences	Honest, timely disclosure	Opportunity for post-consult discussion	Provider communication skills training	Provision of consult record to patient
Schofield, 2006, Australia (13)	MEDLINE, CANLIT, CINAHL, PsychLIT, 1990-2005	57 articles including 2 PGs; 3 SRs; 5 RCTs	33 recommendations for discussing transition from curative to palliative care (10 steps): discussion preparation, eliciting patient understanding, providing information, responding to emotional reactions, negotiating new goals of care, continuity of care, addressing family concerns, acknowledging cultural & linguistic diversity, concluding discussion, post-discussion issues.			V	V	V	\checkmark			V
NICE, 2004, UK (8,9) ^a	MEDLINE (1966), EMBASE (1980), & CINAHL (1982), all to March 2003 CancerLit (dates NR) Cochrane databases ^b	2 SRs; 10 RCTs; 1 RT (no control); 16 other studies	24 recommendations - 4 categories: overview, service configuration & delivery, workforce development, research & development. Provided 2 key recommendations (see text).	\checkmark	V		V	\checkmark		V		
NBCC, 2003, Australia (10,11) °	Databases searched in earlier reviews included MEDLINE & PsychLIT to 1996. Current searches (sources not specified), 1997-2002	1 SR; 5 MAs; 40 RCTs + other	30 guideline statements - 7 categories: general interactional skills, discussing prognosis, discussing treatment options, preparing patients for potentially threatening treatment, emotional & social support, support towards the end of life, exploring and responding to specific concerns. Only the first 4 focus on individual provider-patient communication.				V	V		V	V	
ACCP, 2003, U.S. (12)	NR	NR	 5 recommendations on EOL communication; 3 focused on provider-patient communication (poor-fair evidence): Increase focus on patient experience & improve congruence of treatment with patient preferences, Diagnosis & meaning communicated to patient by an experienced clinician. Day-to-day care coordinator present. Use education resources to improve EOL communication. 	V				V			V	

Table 2. Summary of practice guidelines addressing provider-patient communication.

Abbreviations: ACCP – American College of Chest Physicians; EOL – end-of-life; MA – meta-analysis; NBCC – National Breast Cancer Centre; NICE – National Institute of Clinical Excellence; NR – not reported; PG – practice guideline; R(C)T – randomized (controlled) trial; SR – systematic review.

a Chapter 3 - 'Face to face communication' for adult patients with cancer.

b Cochrane databases searched included: Central Register of Controlled Trials (2001, Issue 4), Cochrane Database of Systematic Reviews (2003, Issue 2), and the Cochrane Effective Practice and Organisation of Care Group (dates NR).

c Chapter 3 - Care to be provided by the treatment team to all patients with cancer.

Author, year	Search sources / dates	Evidence included	Patient population	Interventions studied	Results / Conclusions
Overall com	nunication				
Hagerty, 2005 (14)	MEDLINE, PsycINFO, CINAHL up to Dec 2003	1 RCT + 92 mostly cross- sectional studies, including 8 focused on impact on patient outcomes	Patients with various cancers, mostly early stage. 16-2,331 patients / trial	No trials of Interventions to facilitate communication about prognosis were identified.	 Most research on discussing prognosis is in early stage disease. There is little evidence of the best method of communicating prognosis or of the impact of prognostic information on patient outcomes. Research suggests most patients with early stage disease want to be provided with prognostic information & the communication should be open and honest. Patient preferences for prognostic information may vary.
Davies, 2003 (15)	Range of databases including: MEDLINE, EMBASE, CANCERLIT, CINAHL, PsycINFO, & Cochrane to Mar-May 2000	12 non- comparative cross-sectional or follow-up studies.	All trials included some patients with malignant cerebral glioma. 7-167 patients / trial	No trials of methods for breaking news or giving other information were identified in this patient population.	 Patient awareness of prognosis was variable. Qualitative studies suggested that approach to disclosure should be individualized, with an emphasis on maintaining hope.
Facilitation o	f consult communication				
Kruijver, 2006 (16)	MEDLINE, Nursing & Allied Health Literature 1993-2004	2 RCTs, 1 CT (+ 13 studies on screening / distress recognition)	Outpatients including 57 with lung cancer & 214 with incurable cancer. 57-286 patients / trial	Use of pre-consult QOL questionnaires to facilitate communication during consult.	 Provision of QOL information at consult facilitates provider- patient communication around physical and psychosocial issues, increases patient satisfaction, & positively influences patient wellbeing. The feasibility of using a psychosocial checklist in the clinical rather than research environment needs to be evaluated.
Patient partic	ipation in treatment decis	sion making			
Waljee, 2007 (17)	MEDLINE, EMBASE, CINAHL, Cochrane Network, HAPI 1966-Jun 2006	3 RCTs, 2 CTs, 4 descriptive studies	Breast cancer, stage I or II. Most trials involved newly diagnosed patients. 28-201 patients / trial	 Decisions aids: format: paper, visual, audiotape or computer including photographs, reconstruction, or direct physician involvement length, 21-70 minutes 	 Treatment choice affected by decision aid across 2 RCTs (RR, 1.25; CI, 1.11-1.40) but not 2 CTs (RR, 0.94; CI, 0.72-1.23). Patient knowledge increased by decision aid (pooled standardized mean difference across 3 RCTs, 0.24, 95% CI, 0.03-0.45). Decision aids reduced decisional conflict & increased patient satisfaction with treatment decision (no data provided).
Whelan, 2002 (18)	MEDLINE, 1977-Apr 2001; HealthSTAR, CINAHL, CANCERLIT, PsycINFO, Sociological Abstracts, 1977-Aug 2000; EMBASE, 1995- Aug 2000.	39 studies (16 RCTs) of decision aid effectiveness (+ 22 studies on decision aid development)	Varied cancer types & stages, mostly breast (23) or prostate (11) cancer. 18-409 patients / trial	Decision aids (in 27 treatment studies): • Written materials • Audio or videotapes • Interactive computer • Decision boards • Counselling/ education sessions • Informal decision analysis	 There is insufficient evidence to evaluate the effectiveness of decision aids in treatment-related decisions. Three small randomized trials comparing different decision aids observed no significant differences on patient knowledge, anxiety, decisional conflict or optimism. Two of four small randomized trials comparing decision aids with usual care observed some benefits for patient knowledge (p<0.0001), post-consult anxiety (p<0.001) & patient involvement in decision making (p<0.001).

Table 3. Summary of systematic reviews addressing provider-patient communication.

Author, year	Search sources / dates	Evidence included	Patient population	Interventions studied	Results / Conclusions
Consolidatio	n of consult communicati	on			
Gaston, 2005 (19)	PubMed, 1966-2003 PsycINFO, 1967-2003 CINAHL, 1982-2003	15 RCTs, 32 uncontrolled trials	Patients with advanced locally recurrent or metastatic cancer. 48-749 patients / trial in RCTs; 7-2,331 patients / trial in uncontrolled trials	Interventions to improve information giving & encourage decision making.	 Most patients wanted full information. Desire for active participation in decision making was more variable; approximately 67% supported this. Simple interventions that improve information giving or participation in decision making include question prompt sheets, audio-taping of consults, & use of patient decision aids. Where reported, interventions do not appear to increase anxiety levels.
Scott, 2003 (20)	Range of databases. Most recent update (Jan 2003): MEDLINE, PsycInfo, CINAHL, EMBASE, AMED, Cochrane Library, & Abstracts (Dissertation & Sociological)	11 RCTs; 1 CT	Varied cancer types; advanced (105 patients); early stage (179 patients). Most trials involved initial treatment consults (post-diagnosis). 24-216 patients / trial	Providing patients with videotape or audiotape recordings, or written summaries of their consultations with practitioners.	 Evidence is not strong and conclusions are tentative. The provision of recordings or summaries of key consultations may benefit most adults with cancer, improving information recall & satisfaction with the consult or information received. Consult summaries have not been shown to improve patient anxiety, depression, or QOL. Practitioners should consider offering people tape recordings or written summaries of their consultations.
McPherson, 2001 (21)	MEDLINE, 1980-1999 PsycInfo, 1984-1999 CINAHL, 1982-1999 BIDS, EMBASE, SOCIAL SCISEARCH, IBSS, 1993-1999	10 RCTs	Varied cancer types & stages: terminal stage (21 patients), recent diagnosis or early stage (6 trials, n=36- 304). Most trials involved initial consults. 21-438 patients / trial	Interventions aimed at educating patients: • Interview audiotapes • Audiovisual aids • Interactive media • Provision of written information, booklets, information packages.	 The interventions: Improved some patient outcomes, including knowledge & recall, symptom management, satisfaction, preferences, health care utilization, & affective states, although in most studies there were no effects on psychological factors; Can be used to facilitate the provider-patient communication process; Were mostly inexpensive & not time-consuming; Are not substitutes for good interpersonal skills in the provider. The methods used should be based on individual preferences for information.

Abbreviations: AMED – Allied and Complementary Medicine Database; BIDS – Bath Information and Data Services; CI – 95% confidence interval; HAPI – Hispanic American Periodicals Index; IBSS – International Bibliography of the Social Sciences; CT – non-randomized controlled trial, QOL – quality of life; RCT – randomized controlled trial; RR – risk ratio; SOCIAL SCISEARCH – Social Sciences Citation Index.

Egn

rable 4. Nandomized thats of provider-patient communication, description and quality.								
Trial, Year, Reference	Location	Randomization method described	Statistical power calculation reported	Blinding	Drop-outs described	Balanced Arms	Commercial sponsorship	
Provider com	munication	style						
Strasser,	U.S.	X	Х	To study	Х	NR	Х	
2005 ^a (22)		Cross-over		purpose				
Dowsett,	Australia	Х	Х	NR	Х	NR	Х	
2000 ^a (23)								
Fogarty,	U.S.	Х	Х	NR	ХÞ	X ^c	X	
1999 ^a (24)								
Facilitation of	f consult con	nmunication						
Clayton,	Australia	\checkmark		Consult	\checkmark	X°	Х	
2007 (25)				coders				
Butow, 2004	Australia	Х	Х	Physician	Хp	\checkmark	Х	
(26)				-				
Walker,	U.S.		Х	Х		X °	Х	
2005 (27)								
Patient partic	ipation in de	cision making						
Brown, 2004	Australia	X	Х	Consult	X ^b	X ^c	Х	
(28)				coders				
Whelan,	Canada /	Х	\checkmark	NR	X ^b	\checkmark	Х	
2003 (29)	U.S.							
Deadman,	U.K.	Х	Х	NR	Х	\checkmark	Х	
2001 (30)								

Table 4. Randomized trials of provider-patient communication: description and guality.

Abbreviations: NR – not reported; U.K. – United Kingdom; U.S. – United States of America.

a - Studies involve the use of hypothetical scenarios.

b – Number of withdrawals/drop-outs indicated but reasons for withdrawal/drop-out not provided.

c – Variables unbalanced in each study: greater proportion of nonwhites (71%) than whites (46%) in the intervention group (24); education level higher, and prior professional employment, presence of friend or partner at consult, and prior contact with physician more likely in the intervention group (25); lower proportion of nonwhites (10% vs. 27%) in the intervention group (27); and time since surgery longer in control group (12.7 vs. 8.0 weeks, p=0.06) (28).

Overall Communication

Practice Guidelines

Two of the three guidelines that focused on the general cancer population were considered to be of high quality with differing strengths and weaknesses (8-11). The 2004 NICE guideline on supportive and palliative care for cancer patients included a section on face-to-face communication (9). This guideline examined evidence on interventions targeted at health care providers or systems that intended to improve palliative and supportive care for cancer patients and with a focus on objective measures of professional performance or patient outcomes in a clinical setting. The methods used for the identification and selection of evidence were clearly stated and all the selected evidence was clearly summarized in an associated report (8). However, the links between the recommendations and the evidence were not explicit, the methods used by the guideline panel to formulate the recommendations were not described, and many of the recommendations were general rather than specific. In addition, editorial independence (representing potential author conflicts of interest and editorial influence of any funding bodies) was unclear.

In 2003, the Australian National Health and Medical Research Council (NHMRC) in conjunction with the National Breast Cancer Centre (NBCC) developed wide-ranging evidencebased guidelines on the psychosocial care of adults with cancer (10,11). These guidelines were based on earlier, now rescinded, guidelines developed by the NBCC specifically for women with breast cancer (32) and had high ratings on four of the six domains on the AGREE instrument. The domains of guideline applicability (representing consideration within the guideline of organizational barriers, cost implications, and identification of key monitoring or audit criteria) and editorial independence received lower scores because limited information was provided. Although the guidelines cited a wide range of evidence, the literature search and selection criteria were not clearly stated within the report and the methods used for developing and reaching consensus upon the recommendations were not described in detail. The *Introduction* section of the guidelines provided broad guideline statements, with associated evidence citations; however, the most useful recommendations for health care providers were spread throughout the guideline and consisted of detailed, action-oriented recommendations that addressed communication at different stages of the disease and treatment process. The extent to which these more focused recommendations were based on research evidence was less clear.

Key aspects of communication identified by each guideline are indicated in Table 2. Both high-quality guidelines identified core aspects of communication that were consistent for all cancer patients at all disease and treatment stages (8-11). These included open, honest, and timely provision of information to the patient and support for the utility of communication skills training courses for professionals. Other aspects of effective communication may vary across patients and within patients across time, including the appropriate form (e.g., written or taped consult summaries), content (e.g., extent of prognostic information provided; use of numbers, statistics, visual aids), and the timing of information (e.g., provision of prognostic information or treatment decision making at first or later consults). Both guidelines also emphasized the importance of exploring patient preferences for information, patient involvement in decision making, and additional support on an ongoing basis.

In addition, the NICE guideline (8,9) included two key recommendations:

- 1. A senior clinician, assessed as an effective communicator and with advanced level training, should communicate significant news, although all staff should be able to respond appropriately to patients' and caregivers' questions before referring to a senior colleague.
- 2. The outcome of key consultations should be communicated to other involved professionals and recorded in the patients' notes, with a permanent record offered to the patient.

In contrast, the NBCC guidelines (10,11) provided a wide range of very specific and practical recommendations for communication including the use of empathic expression, open-ended questions, and active listening; identification of patient recall and understanding aids; and the use of a variety of media in discussing information with patients.

Systematic Reviews

Two reviews evaluated a range of communication preferences and strategies (14,15). Hagerty et al conducted a systematic review focusing on the communication of prognosis to cancer patients (14). This review was partially funded by the NBCC of Australia, which completed a related guideline in 2003 (discussed above) (10). The review was extensive; however, it provided limited information on how studies were selected, evaluated, or combined to reach conclusions (14). Most of the 93 eligible studies, organized to address 11 questions, were observational with a cross-sectional or longitudinal design and used interviews or surveys to collect data. Only eight trials, including three retrospective designs, explicitly considered *the impact of that information on patient outcomes*. Factors that tended to increase patient satisfaction or decrease anxiety or depression in individual studies included the discussion of life expectancy during the consult, the disclosure of prognosis and a longer length of consult when prognosis was discussed, the consultation environment, and the physician manner of disclosure. Information disclosure was not found to increase patient anxiety levels, although results were mixed on the impact on patients of awareness or acknowledgement of prognosis.

Across the 23 trials addressing *patient preferences for prognostic information*, including one randomized trial, most patients indicated they wanted to receive diagnostic and prognostic

information such as the chance of cure, the extent of disease spread, and possible treatment side effects. However, it was also considered important for providers to check patients' preferences before disclosing such information. Low anxiety levels and female gender were associated with greater interest in receiving prognostic information in four additional studies. Fourteen studies focused on patient preferences for style of communicating prognosis, considering a wide variety of issues. The most consistent finding was that honesty, trust, and hope were important aspects of the provider-patient communication process. Across 19 trials, patient understanding and awareness of prognostic information was generally found to be limited, with misunderstandings common around prognosis, chance of cure, expected survival, and aims of treatment. The need for clear communication, including use of different techniques, and checking for patient understanding by the provider was emphasized. The section on interventions to facilitate prognostic discussion commented on the potential utility of pre-consult question prompt lists and communication skills training for providers. Other issues considered in the review included: disclosure of prognosis to family members, physicians views on communication of prognosis, current practice regarding delivery of prognostic information, and cultural differences in preferences and understanding.

The Davies and Higginson review focused on patients with malignant cerebral glioma (15) and on studies that examined patient understanding of disease prognosis or patient response, including psychological distress, to communication of prognosis or consult. The results were consistent with those found in the broader systematic review. No interventional studies on methods of provider-patient communication were identified in this patient population.

Provider Communication Style

Systematic Reviews

The review by Hagerty et al (14), discussed previously, evaluated *patient preferences for style of communicating prognosis* across 14 non-comparative studies involving 32-351 patients with early stage disease and 16-137 patients with advanced disease or under palliative care. Consistent aspects of provider communication considered important by patients included honesty, trust, and provision of hope.

Randomized Trials

Three randomized trials explored different aspects of provider communication style and are summarized in Table 5 (22-24). All trials involved current or past cancer patients evaluating provider-patient interactions in videotapes of simulated consults. The aspects of communication explored included whether the physician was standing versus sitting during the interaction (22), physician use of a predefined patient-centred or physician-centred consult style (23), and the addition of short 'compassion'-oriented statements to standard consults (24). In the three studies, most patients were white (80-84%) (22,24), married (66-68%) (22-24), and had post-secondary education (65%; mean, 15 years) (22,24) or a minimum of grade 12 (68%) (23). The videos were evaluated by patients in two of the trials and considered realistic (22,24).

In a small, randomized cross-over study, Strasser et al presented a video with the physician first sitting, then standing, during the consult and vice versa (22). Overall, patients did not show a preference for physician sitting during the consult (51%), and there were no statistically significant differences between scenarios on patient satisfaction with communication or patient rating of physician attributes or compassion. An order effect was observed, with a higher proportion of patients preferring the sitting scenario when it was presented second (69%) but not first (32%). After patients were informed of the study purpose, most indicated a preference for their own physician to sit when talking with them (81%).

Trial, Year	Interventions	N/ N _c	Population	Outcomes (Primary *)	Results
Provider com	munication style				
Strasser, 2005 (22)	Video simulation: inpatient consult on options after disease progression, with physician standing vs. sitting	69/69	Varied advanced cancers, with 71% metastatic	 Communication style preference* Physician compassion and attributes (both 5-item semantic differential scales)^a Perception of consult duration Satisfaction with communication (PSQ) 	 Preference: sitting (51%), standing (23%), none (26%). Patient-rated physician attributes and satisfaction with consultation between posture styles, NS. Period effect with strong preference for second sequence in each video (p=0.003).
Dowsett, 2000 (23)	Video simulation: good vs. poor prognosis consult presented in 6 settings: patient vs. doctor-centred style ^b for diagnosis, prognosis & treatment	161 [°] / 113	Previously treated breast cancer patients and relatives/ friends	 Consult style preference Consult satisfaction (7-point Likert scale) 	 Good vs. poor prognosis, NS. In all settings, patient-centred style preferred (p<0.05 except for good prognosis treatment discussion.
Fogarty, 1999 (24)	Video simulation: consult on treatment options for metastatic disease vs. same consult with short enhanced physician compassion segments	210 [°] / 123	Breast cancer survivors and relatives/ friends	 Perception of physician compassion and attributes (both 5 item semantic differential scales) Anxiety (STAI) Knowledge recall Treatment decision 	 'Compassion' physician rated higher on all aspects of compassion (p<0.001) and all but one attribute (p<0.05). No difference in treatment choices (p=0.95) Following compassion video: Knowledge recall lower (28.37/54 vs. 30.38, p=0.015 Post-consult anxiety lower (40.0/80 vs. 44.7, p=0.011 ^d)
Facilitation of	f consult communication				
Clayton, 2007 (25)	Routine consultation with vs. without pre-consult 16- page, 112 question prompt list provided 20-30 minutes pre-consult	174/ 174	Advanced cancer	 Number of questions asked*, items discussed (consult audiotape analysis) Consistency with patient information preferences (CISQ) Patient & physician satisfaction with consult (Roter) Patient anxiety (STAI) Consult duration 	 Intervention group higher on: Number patient (5.4 vs. 2.3, p<0.0001) or caregiver (4.4 vs. 2.1, p=0.0005) questions asked Number of items discussed (20.9 vs. 17.0, p<0.0001) Consult time (37.8 vs. 30.5 mins, p=0.002) No significant group differences on: Patient satisfaction (110.1/125 vs. 110.3) Patient anxiety at 24-hours or 3 weeks
Butow, 2004 (26)	Cancer consultation preparation package (booklets on decision making, patient rights and the treatment centre) vs. treatment centre booklet given ≥2 days prior to first medical or radiation oncology consult	164 ^e / 164	Varied cancers, 33% metastatic	 Preferences for Information (CISQ) and decisional control Patient asking questions & receiving support (KHOS) Satisfaction with decision-making process (5-point Likert scale) Satisfaction with consult (Roter) Anxiety (STAI) / depression (BDI) 	 No significant group differences on: Reported involvement in decision making Satisfaction with consult or decision making Anxiety/depression levels No differences in physician behaviours Intervention group higher on number of questions asked (mean 13 vs. 9, p=0.009), interruptions (median, 1.01 vs. 0.71, p=0.08) & information challenges (median, 2 vs. 1, p=0.05) Intervention patients less likely to achieve preferred involvement in decision making (35% vs. 22%, p=0.06)
Walker, 2005 (27)	Videotape introducing clinic and health care professionals vs. written pamphlet prior to first	95/ 95	Recently diagnosed breast cancer patients	 Patient distress (STAI, CES-D, MMAC) Quality of life (FACT-G) Patient satisfaction with consult, orientation, informational preparedness, & 	Structural equation modelling found adjusted main effects for videotape on: • Satisfaction with orientation (p=0.049) • Preparedness for consult (p=0.05)

Table 5. Randomized trials of provider-patient communication: results.

Trial, Year	Interventions	N/ Nc	Population	Outcomes (Primary *)	Results
	clinic visit.			decision-making participation (Likert scale)	 Readiness to ask questions (p=0.05)
Patient partic	ipation in decision making				
Brown, 2004 (28)	Information booklet & personalized videotape on decision making vs. general booklet on cancer issues prior to first medical oncology consult	65/ 65	Females recently diagnosed with cancer. Most with breast cancer (69%) at an early stage (88%)	 Information seeking / decision-making involvement (consult audiotape analysis) Declaration of consult preference Information (CISQ) and decisional control preferences Satisfaction with consult (PSCS) and decision making Decisional conflict (DCS) Anxiety (STAI) / depression (BDI) 	 Information seeking & preferences for involvement in decision making, NS. Intervention group more likely to declare information (65% vs. 41%, p<0.1) & treatment preferences (61% vs. 38%, p<0.1). Post-consult depression, decisional conflict, and satisfaction with consult and decision making, NS Anxiety lower in intervention group at baseline (40.2/80 vs. 48.6, p=0.01) and 2 weeks post-consult (32.3 vs. 40.3, p=0.01) but not immediately post-consult or 6 months later.
Whelan, 2003 (29)	First post-surgery medical oncology consult with vs. without a decision aid	176/ 176	Breast cancer, lymph node- negative post- surgery	 Patient knowledge* (25-items) Patient satisfaction with decision making* (DCS 4 item decision-making subscale) Anxiety (STAI) Preference for decision-making role Decision-making process Treatment chosen Physician decision-making satisfaction Length of consult 	 Decision aid group: Higher 1-week post-consult knowledge (80/100 vs. 72, p<0.001) Higher satisfaction with decision making up to 12 months post-consult (p=0.032). Mean anxiety at 1-week, p=NS.
Deadman, 2001 (30)	Non-rand compulsory mastectomy group vs. randomization to treatment decision endorsed by surgeon vs. left to patient	80 / 80 + 34 not ran- dom	Newly diagnosed breast cancer, stage I or II	 Psychological morbidity – 10 scales, 23 measures including adjustment (MAC); mood (Leeds; STAI); body image (Body & Breast satisfaction); sociability, (FNE; SAD); marital satisfaction; self-esteem (PERI subscale); health locus of control 	 Higher morbidity with compulsory group, especially pre-operatively (p<0.05, mental adjustment), at 4m follow-up (p<0.05 on 8 of 23 measures including mental adjustment, mood, body image, self-esteem & internal locus of control), and 9m follow-up (mental adjustment, body image). Few significant (p<0.05) benefits for patient vs. surgeon decision groups (pre-operative: mental adjustment, body image; 15m follow-up, depression). Belief in powerful others bigher with patient decision group (p<0.01)

Abbreviations: BDI – Beck Depression Inventory; CES-D – Centre for Epidemiologic Studies-Depression; CISQ – Cassileth Information Styles Questionnaire; DCS – Decisional Conflict Scale; FACT-G – Functional Assessment of Cancer Therapy – General; FNE – Fear of Negative Evaluation; KHOS – Krantz Health Opinion Survey; m – month(s); (M)MAC – (Mini) Mental Adjustment to Cancer scale; N – number of patients randomized; Nc – Number of cancer patients randomized; NS – not statistically significant; PERI - Psychiatric Epidemiology Research Interview; PSCS (Roter) – Patient Satisfaction with Consultation Scale; PSQ – Patient Satisfaction Questionnaire; SAD – Social Avoidance and Distress; STAI – Spielberger State-Trait Anxiety Inventory; vs. – versus.

a Scales evaluate physician attributes (wants best for patient, patient involvement in decision making, encourage patient questions, acknowledge patient emotions, and care for patients) and physician compassion (warm/cold, pleasant/unpleasant, compassionate/distant, sensitive/insensitive, caring/uncaring).

b Eleven dichotomous behaviours differentiated the patient/physician consult style: tone of voice, eye contact, location, understandability, asking about and allowing expression of feelings, listening, showing empathy, checking understanding, acknowledging patient concerns, and involving patient in decision making. c Included a separate group of relatives and friends of cancer patients.

d Controlling for baseline scores.

e 36 of 200 randomized patients were not included in analysis: ineligible (18), previous oncology consult (9), cancelled or withdrew (9).

Dowsett et al randomized participants to view a good versus poor prognosis videotaped consult with variations by consult type (diagnosis, treatment, or prognosis) and physician communication style (patient or physician-centred) (23). Results for patients and their relatives/friends were not significantly different and were pooled. Patient-consult preferences and satisfaction were not significant different between prognostic conditions, although the patient-centred consult style was generally preferred. Satisfaction with the consult was generally positive, although the score range was restricted (means, 4.4-5.3). Satisfaction was significantly higher with the patient-centred consult style for diagnosis (mean, 5.3 versus [vs.] 4.8, p=0.01, particularly when the prognosis was poor, p=0.04) and with the physician-centred consult style for treatment (mean, 4.9 vs. 4.4, p=0.02, particularly when the prognosis was good, p=0.01).

Participants in the trial by Fogarty et al viewed consult videotapes with and without two short 'enhanced physician compassion' segments (24). Segments were approximately 40 seconds long and involved the physician supporting patients and acknowledging and validating their psychological and emotional concerns. Anxiety increased in all participants following video presentation (mean, 31.6 at baseline vs. 42.0 post-video, p<0.001), although post-test scores were significantly lower for the intervention group after controlling for baseline anxiety. Knowledge recall was lower in the intervention group, although the two-point difference may not be clinically important, and ratings of physician compassion and other attributes were significantly higher, except for the belief that the physician wanted the best for the patient. Although outcomes for survivor and non-cancer groups were generally similar, survivors were more likely to choose the riskier versus standard treatment option (54% vs. 29%) compared with the non-cancer group (41% for both options, p=0.046).

Facilitation of Communication during Consultations Systematic Reviews

Kruijver et al included three studies examining the impact on provider-patient communication of a pre-consult patient-completed QOL assessment (European Organization for Research and Treatment of Cancer, QLQ-C30 used in all trials). They found that patients reported that more issues were addressed during a consult when their physician had access to the pre-consult QOL summary (16). In the randomized trials, both involving >200 patients, the intervention was associated with significantly higher patient satisfaction with physician emotional support (Patient Satisfaction Questionnaire, PSQ-C) but a non-significant benefit on patient emotional well-being (Health Related Quality of Life scale, p=0.08). No significant benefits were reported for the intervention group in patient satisfaction (Patient Satisfaction questionnaire, PIDS) or on an objective measure of the number of issues addressed in the non-randomized, controlled study.

In a broad, high quality review of strategies to improve information giving and patient decision making, Gaston et al organized the literature into four themes (19). Under *interventions to improve participation in decision making,* they evaluated seven trials that facilitated general patient participation in the consultation. Of those, four randomized controlled trials (60-318 patients) and one uncontrolled trial (23 patients) evaluated the use of pre-consult question prompt sheets and found that the intervention increased the number of questions asked by patients generally (two trials) or specific to prognosis (one trial), was associated with no increase (one trial) or a decrease (one trial) in anxiety, and was generally considered helpful (two trials). Prognosis was the issue of interest most often identified by patients using prompt sheets. Hagerty et al, discussed previously, reached similar conclusions in a review of a subset of those studies (14).

Randomized Trials

Relevant trials included in the Kruijver et al and Gaston et al (19) reviews are summarized above and are not included here. Three additional trials evaluated different pre-consult strategies for facilitating communication during a cancer consult, including a question prompt booklet (QPL) (25), a multi-component Cancer Consultation Preparation Package (CCPP) (26), and an introductory clinic videotape (27). Most patients were married or cohabiting (59-68%) (25-27), with mean ages of between 52 (27) and 65 (25) years, and in the one study reporting race, most participants were white (82%) (27). The majority of patients were well educated (\geq 12 years education) in two trials (26,27) but had <12 years schooling (67%) in one trial (25).

Participants receiving the QPL prior to consultation with a palliative care physician asked significantly more questions and discussed significantly more issues, particularly for seven of the nine identified topics (palliative care service, prognosis, quality of life, support, professional care, end-of-life issues, and caregiver issues), than the control group (25). This was consistent with the results of the review by Gaston et al (19). There were no differences between groups on the number of concerns raised (non-question statements), overall measures of achievement of information needs at 24 hours post-consult, patient anxiety at 24 hours or 3 weeks post-consult, patient satisfaction with the consult (generally high), or physician satisfaction with the consult communication. Patients in the intervention group found the QPL helpful (96% post-consult) and asked more questions when the physician endorsed it (p<0.0001).

A question prompt sheet was also included in the CCPP distributed to patients in the trial by Butow et al (26). Both the CCPP and control groups found the documents to be useful and easy to understand, although the CCPP group was significantly more anxious than the control group pre-consult (mean, 42 vs. 38, p=0.04). The CCPP group asked more questions during the consult, specifically on prognosis (median, 1 vs. 0, p=0.001). A behaviour analysis of consult transcripts revealed similar rates of active patient behaviour across groups and there were no significant differences in physician behaviour. Post-consult, anxiety decreased in both groups and no significant group differences were detected on any outcome.

Walker and Podbilewicz-Schuller used structural equation modelling to estimate the effect of a pre-consult videotape compared with an information booklet on patient outcomes, while controlling for significant baseline patient characteristics, including distress (anxiety, depression, and adjustment) (27). In addition to the main effects summarized in Table 5, several significant interactions were observed (p<0.05), although the number of patients in some subgroups was small. The interactions suggested the videotape mitigated follow-up distress in unmarried patients and QOL in patients with a history of mental health treatment (p=0.084), and increased satisfaction with the consult in minority patients (p=0.007).

Patient Participation in Decision Making

Systematic Reviews

In the Gaston et al review discussed above, thirteen trials examined *interventions to improve participation in decision making*, including four small uncontrolled trials (n=20-81) of treatment-related decision aids (19). The decision aids explored included decision cards, decision boards, and a multi-method approach (tape, booklet, and worksheet). Results suggested the aids increased patient knowledge and reduced decisional uncertainty (two trials), did not increase anxiety (one trial), and were acceptable to patients (two trials). One trial found that patients overestimated the potential for treatment benefits and one found patients with recurrent cancer were more likely to prefer aggressive over palliative treatment. Preference for involvement in decision making was evaluated across 11 descriptive studies, with approximately 67% of palliative patients (four trials) expressing a preference for participation. The results of two small studies (n=80-105), suggest that desire to patients preferring less control and those improving preferring greater involvement.

In a high quality 2002 review published by the Agency for Healthcare Research and Quality (AHRQ), 61 trials of cancer-related decision aids were evaluated, with 27 trials of treatmentrelated decision aids, including brochures; decision boards; audiotapes or videotapes; interactive computer programs, educational scripts or counselling, and informal decision analysis (18). Only one of the seven treatment-related randomized controlled trials (RCTs), including 136 patients and comparing two decision aids, was rated as high in methodological quality; all non-randomized trials were of low to modest quality, and only some directly required provider-patient interaction. Three of the seven RCTs compared different decision aids and reported no differences in outcomes including treatment chosen or patient knowledge, anxiety, decision conflict or optimism (n=46-136). Among the four RCTs that compared decision aids with usual care, one small trial (n=34) found that provision of an audiotape of the initial consult increased patient knowledge (no difference after consult, p<0.0001 after one week) and decreased post-consult anxiety level (p<0.0001). In another trial (n=60), patients were more active in treatment decision making (p<0.001) following a combination of counselling plus an information pamphlet and the option of a consult audiotape, although the trial groups were not well balanced at baseline. Limited outcome information was reported for two other trials (n=24-100). Overall, limited evidence was available on the use of treatment-related decision aids.

In a more recent systematic review involving nine trials, Waljee et al evaluated decision aids specifically related to surgical treatment options for early stage breast cancer (17). Two of the three randomized trials were also included in the AHRQ review (18) and examined the use of a hand-held decision board, an audiotape workbook, and an interactive, multimedia program. Six of the trials were office-based, and only two required direct physician involvement. Limited details were provided on study selection and evaluation process. Patient knowledge about breast cancer and treatment options significantly increased after use of a decision aid in five of six individual trials and across the three randomized trials (pooled standardized mean difference, 0.24; 95% confidence interval [CI], 0.03-0.45). Although other benefits were reported for decision aids (decreased decisional conflict, increased patient satisfaction with treatment decision, improved quality of life, and no increase in anxiety or depression), trial data were not summarized in the review. Most patients reportedly found the decision aid a useful communication tool (62%) and would recommend it to others (98%), although qualitative studies suggest only 69% obtained sufficient information for participation in treatment decisions. In the two trials reporting their views, surgeons found the decision aid facilitated communication, particularly with pictorial information, although barriers to use included the need to involve ancillary staff and the need for space to view the decision aid.

Randomized Trials

Three additional randomized trials examined interventions to improve patient participation in decision making, including the pre-consult provision of a booklet on decision making along with a 15-minute personalized video of the patient's oncologist discussing treatment options in a simulated consult (28), use of a treatment decision board during consultation (29), patient-counsellor discussion of treatment options and the patient making the final treatment decision (30). Most patients were married or cohabiting (74-76%) (28-30), with mean ages of between 51 (28,29) and 56 (30) years. A minority of patients had post-secondary or 12 years or more education 40-46% (28,29).

Overall, Brown et al found 86-89% of patients wanted as much information as possible both pre- and post-consult and patient preference for involvement in decision making changed over time but was similar for patients in the intervention (decision-making booklet and personalized video) and control groups (28). There were no post-consult group differences on patient distress or satisfaction measures and differences in anxiety were inconsistent over time. Physician behaviour was generally similar across groups, although they introduced a higher number of new themes with the intervention group (mean, 23.5 vs.18.0, p=0.06). Across the

80% of first consults transcribed and analyzed, significant group differences were observed on only two of the 29 coded items (intervention higher): declaring perspectives on treatment costs (74% vs. 45%, p=0.04) or benefits (61% vs. 38%, p=0.03). The authors noted that a lack of score variability might have limited the ability of the trial to detect significant differences.

In the trial by Whelan et al, breast cancer patients attending a consult on adjuvant chemotherapy were randomized to usual care with or without the use of a decision board (29). The board, which provides treatment-specific written and graphical information in a step-by-step process, was presented to patients by a nurse, although the medical oncologist introduced the treatment options and returned to answer patient questions following the presentation. Treatment knowledge and satisfaction with decision making were higher in the intervention group and the number of patients expressing a preference for an active role in treatment significantly increased (p=0.033). No differences were detected on anxiety over the 12 month study period, decision-making processes, treatment chosen, physician satisfaction with decision making or length of medical consult.

Deadman et al assessed the psychological impact (23 measures at four different time points) of patients being given a choice of treatment and taking responsibility for that choice (30). The impact of choice was evaluated in a non-randomized group of 34 patients undergoing compulsory mastectomy and 80 patients given a choice between mastectomy and breast conservation procedures. Taking responsibility for treatment decisions was explored, following patient-counsellor discussion of treatment options, by randomizing the 'choice' of patients to have the physician recommend the patient-preferred treatment option or requiring the patient to explicitly make the final treatment decision. Only significant results were presented and data for nine and 15 month follow-up were difficult to interpret due to loss to follow-up (41-88%). Overall, morbidity was higher (p<0.05) in the compulsory versus choice group on three measures pre-operatively and eight measures at four month follow-up. Morbidity for patients undergoing compulsory mastectomy (n=34) versus those choosing mastectomy (n=10) was generally higher although differences were significant only on a body image measure at four months and at nine months. For patients given a choice of treatment, few significant differences were observed between the randomized groups.

Consolidation of Communication during Consultations Systematic Reviews

Two high-quality reviews focused on general strategies to improve information giving and patient decision making (19) or the more specific strategy of providing patients with consult recordings or summaries (20). Gaston et al, discussed above, organized the literature into four themes related to information giving and decision making in patients with advanced cancer (19). Across the 11 descriptive studies evaluating patient preference for participation in decision making, most patients with advanced cancer wanted full information about their disease. Misunderstandings of the extent or prognosis of disease, or of treatment aims and potential outcomes, were common in the 11 descriptive studies examining patient knowledge of these topics. The 12 trials of interventions to improve information giving included nine randomized trials; most examined the provision of consult audio tapes, although some provided more general video tapes or consult summary letters. Most patients liked receiving the consult tapes and showed improvement in patient knowledge (three studies) and satisfaction (four studies). The trials included under interventions to improve participation in decision making were discussed previously. Gaston et al indicated that providing patients with more information was not generally found to increase patient anxiety levels; however, they emphasized that only English literature was included in their review, and the potential for cultural differences in preferences for information or involvement in decision making should be considered.

Scott et al reviewed mainly randomized controlled trials on the use of consult summaries with cancer patients (20), including six of the studies from the Gaston et al review (19). Most

trials included only initial treatment consults, although two focused on diagnosis or bad news consults. Most patients (83-96%) found the use of consult tapes or summary letters to be useful and information recall and satisfaction with the consult or the information received was significantly better with the intervention in just over half of the trials. None of the seven studies evaluating patient well-being detected a significant benefit with the intervention on anxiety, depression or QOL. Three trials reported subgroup analyses of the provision of good versus bad news. In one study (48 patients), patients receiving bad news found a summary letter significantly more useful than did those receiving good news. In two other studies (n=117 and n=182, respectively), patients with poor prognoses who had received consultation tapes had significantly higher psychiatric morbidity at follow-up than those with better prognoses, and those who were anxious and given bad news did not like having a summary letter or consult tape as a reminder. The one trial (n=182) that compared the provision of consult audio tapes with a summary letter found patients to be more satisfied with the tape, although information recall was not significantly different. Scott et al commented on a number of limitations in the available studies, including the impracticality of blinding, because of the nature of the interventions, a particular concern with subjective outcomes; the evaluation of interventions for only a single consult with short-term follow-up; and lack of consideration of costs in the trials, which could affect the feasibility of the interventions if they were routinely applied.

One additional moderate quality review focused on methods for giving information (21). That review mainly included studies involving the use of handouts, booklets, or document packages (21). Two studies individualized the information provided to patients and two studies that assessed the use of consult audiotapes were also included in the broader systematic review by Scott et al (20).

Randomized Trials

No additional randomized trials addressing the consolidation of communication during consultations were identified.

DISCUSSION AND CONCLUSIONS

The literature examining the patient-provider communication interface is large, challenging to integrate, and of varying quality. What is clear is that the way a clinician and treatment team relates to and communicates with a patient can benefit the patient and their family. The potential benefit includes effects on psychosocial adjustment, decision making, treatment compliance, and satisfaction with care. What is also clear is that (i) there is no single strategy or collection of strategies that work best for all people, (ii) how the interaction unfolds must be individualized to meet patient communication preferences and styles, and (iii) there is considerable variation in patient preference to be active in the decision-making process. Relatively consistent findings emerged across studies, including a reduction in the distress associated with discussion of life expectancy and prognosis during consultations, and a greater preference for women and for those with low levels of anxiety to receive information. Techniques to increase patient participation in decision making were associated with greater satisfaction, though not necessarily decreased distress. The provision of written summaries of consultations was preferred by many patients but was associated with increased distress in patients with poorer prognoses. In a few, if any, of the studies were cultural factors fully addressed, though their influence on preferences for communication may be extremely significant. In addition, some evidence suggests that preferences may vary considerably based on age, gender, disease type, stage, and prognosis. Further, the nonverbal aspects of communication and of empathy may be as important as or more important than the specific techniques that are used.

Our intent with this report is to provide very practical evidence-based recommendations to improve the quality of communication between patients and providers. To this end, although the

complete evidentiary base was appraised and used by the Patient-Provider Communication Working Group to inform their deliberations (see below), it was decided that the NBCC–NCCI guideline would serve as the foundation for the Ontario recommendations.

CONFLICT OF INTEREST

None declared.

JOURNAL REFERENCES

The following recommendations article has been published in *Current Oncology* (http://www.current-oncology.com/index.php/oncology):

 Rodin G, Zimmermann C, Mayer C, Howell D, Katz M, Sussman J, et al. Clinician– patient communication: evidence-based recommendations to guide practice in cancer. Curr Oncol. 2009;16(6):42-9.

The following systematic review (2009 © Springer-Verlag Berlin Heidelberg) has been published in *Supportive Care in Cancer* (<u>http://www.springerlink.com/</u>):

• Rodin G, Mackay JA, Zimmermann C, Mayer C, Howell D, Katz M, et al. Clinician-patient communication: a systematic review. Support Care Cancer. 2009 Jun;17(6):627-44. Epub 2009 Mar 4. doi: 10.1007/s00520-009-0601-y.

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Appendix 1. Members of the PEBC Provider-Patient Communications Working Group.

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Appendix 2. Ten key points for provider-patient communication.

- 1. Take into account the needs and preferences of the patient in the communication dialogue being sensitive to cultural background.
- 2. Identify and adhere to the person's stated preferences in the approach to information exchange and decision making.
- 3. Show regard and concern for the person by using verbal and non-verbal behaviour that is appropriate for the age, cultural background and preferences of the patient.
- 4. Ensure that significant news is given in person, in a quiet, private place and allow enough uninterrupted time.
- 5. Communicate information in a way which is honest but provides room for hope and communicates your willingness to be there for ongoing support.
- 6. Consider strategies to aid recall and understanding (i.e., allow questions, use diagrams, write down or tape the consultation).
- 7. Allow patients to express their understanding and feelings about the information that was given to them.
- 8. Allow the opportunity for debriefing, discussion and support following the communication of critical and upsetting information.

ducation

- 9. Communicate in clear, simple terms avoiding medical jargon that is sensitive to culture.
- 10. Allow for communication with patients individually and as a part of a family unit or support system.

•••	Search terms by database					
Search category	MEDLINE, HealthSTAR, CINAHL (variations in search wording by database)	PsycINFO	EMBASE	Cochrane databases (Systematic Reviews & Controlled Trials)		
Disease	Subject headings: Neoplasms Carcinoma	Subject headings: Neoplasms	Subject headings: Cancer Carcinoma Neoplasm	Subject headings: Neoplasms Carcinoma		
Intervention	Subject headings: Professional-patient relations Truth disclosure Diagnosis Prognosis Text word: bad news Decision Making *Decision Support techniques (MEDLINE) Decision Making, Patient (CINAHL) combined with text word 'treatment' (Medline)	Subject headings: Communication terms (communication; communication barriers; communication skills; nonverbal communication; verbal communication; oral communication; written communication) combined with provider terms (physicians, nurses, clinicians, doctors, health care professionals) Diagnosis Prognosis Text word: bad news truth disclos: Decision Making/ combined with text words: treatment decision, choice, or preference or decision aid	Subject headings: Tumor diagnosis Diagnosis Prognosis Text word: bad news truth disclos Medical Decision Making/ combined with Consultation Interpersonal communication Medical Decision Making/ combined with consultation Interpersonal communication truth disclos	Subject headings: Professional-Patient Relations Communication Communication barriers Language Nonverbal communication Verbal behaviour Decision Making		
	Text words used in all databases: ((nurse: or provider: or physician: or clinician: or worker: or professional: or doctor:) adj3 (patient: or client:) adj (communication or interaction or relations or relationship))					
Publication & study types; Trial methods	Subject headings & publication types: Guideline Meta-analysis Randomized controlled trials Controlled clinical trials Random allocation Double-blind method (or studies) Single-blind method (or studies) Triple-blind studies Case-control studies	Subject headings & publication types: Treatment guidelines Professional standards Meta-Analysis Clinical trials Prospective studies Cohort analysis Treatment effectiveness evaluation Experimental design Between groups design	Subject headings & publication types: Practice guideline Meta-analysis "Systematic review" Control group Controlled study Double-blind procedure Single blind procedure Triple blind procedure Randomized controlled trial	Not applicable		

Appendix 2. Search terms used for electronic databases.

Comparative study	Longitudinal studies	Comparative study	
Control groups	Repeated measures	Nonequivalent control group	
Clinical trials	Hypothesis testing/	Case-control study	
Cohort studies	Quantitative methods	Pretest postfest control group design	
Multicenter studies	Qualitative research	Clinical study	
Intervention studies (or trials)		Cohort analysis	
Cross-sectional studies	Text words:	Correlational study	
Prospective studies	Guideline:	Crossover procedure	
Cross over studies	Mota analysis: motaana: motanal:	Qualitative research	
Matched-pair analysis	Systematic review overview or	Experimental design	
Random assignment	synthesis:	Experimental design	
Pretest-posttest control group design	Pandom	Parallel design	
Pretest-positiest design	Control	Protect postfect design	
Nonrandomized trials	Control	Quantitative study	
Correlational studies		Quantitative study	
Oualitative studies		Text words:	
Quantitative studies		Guideline:	
Empirical research		Meta-analysis: metaana: metanal:	
Observation		Systematic review overview or	
Qualitative research		synthesis	
Qualitative recourses		Synthoolo	
Text words:			
Guideline:			
Meta-analysis: metaana:, metanal:			
Systematic review, overview, or			
synthesis;			
Random			
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Evidence-Based Series #19-2: Section 3

Provider-Patient Communication: EBS Development Methods and External Review Process

G. Rodin, J.A. Mackay, C. Zimmerman, C. Mayer, D. Howell, M. Katz, J. Sussman, S. McNair, and M. Brouwers

A Quality Initiative of the Program in Evidence-Based Care (PEBC), Cancer Care Ontario (CCO)

Report Date: March 17, 2008

THE PROGRAM IN EVIDENCE-BASED CARE

The Program in Evidence-based Care (PEBC) is an initiative of the Ontario provincial cancer system, Cancer Care Ontario (CCO) (1). The PEBC mandate is to improve the lives of Ontarians affected by cancer, through the development, dissemination, implementation, and evaluation of evidence-based products designed to facilitate clinical, planning, and policy decisions about cancer care.

The PEBC supports a network of disease-specific panels, termed Disease Site Groups (DSGs) and Guideline Development Groups (GDGs), as well as other Groups or Panels called together for a specific topic, all mandated to develop the PEBC products. These panels are comprised of clinicians, other health care providers and decision makers, methodologists, and community representatives from across the province.

The PEBC is well known for producing evidence-based clinical practice and organizational guidelines, known as Evidence-based Series (EBS) reports, using the methods of the Practice Guidelines Development Cycle (1,2). The EBS report consists of a comprehensive evidentiary review (typically a systematic review) of the evidence on a specific cancer care topic, an interpretation of and consensus agreement on that evidence by our Groups or Panels, the resulting recommendations, and an external review by Ontario clinicians and other stakeholders in the province for whom the topic is relevant. The PEBC has a formal standardized process to ensure the currency of each guideline, through the periodic review and evaluation of the scientific literature and, where appropriate, the integration of that literature with the original guideline information.

The Evidence-Based Series

Each EBS is comprised of three sections:

- Section 1: Guideline Recommendations. Contains the recommendations derived from the evidentiary review, its interpretation by the panel involved, and a formalized external review in Ontario by review participants.
- Section 2: Evidentiary Base. Presents the comprehensive evidentiary/systematic review of the clinical and scientific research on the topic and the conclusions reached by the panel.
- Section 3: EBS Development Methods and External Review Process. Summarizes the EBS development process and the results of the formal external review by Ontario practitioners of the draft version of <u>Section 1: Recommendations</u> and <u>Section 2:</u> <u>Evidentiary Base</u>.

DEVELOPMENT OF THIS EVIDENCE-BASED SERIES Development and Internal Review

This EBS was developed by the PEBC Provider-Patient Communications Working Group. The series is a convenient and up-to-date source of the best available evidence on Cancer Pain Management, developed through a review of the evidentiary base, evidence synthesis, and input from external review participants in Ontario. The Working Group was made up of palliative care physicians, psychiatrists, nurses, oncologists, a social worker, and methodologists.

External Review by Ontario Clinicians

Following the review and discussion of <u>Section 1: Recommendations</u> and <u>Section 2:</u> <u>Evidentiary Base</u> of this EBS, the PEBC Provider-Patient Communications Working Group circulated Sections 1 and 2 to external review participants in Ontario for review and feedback. Box 1 summarizes the draft recommendations and supporting evidence developed by the PEBC Provider-Patient Communications Working Group.

Methods

Feedback was obtained through a mailed survey of 110 external review participants in Ontario (including nurses, social workers, patient educators, palliative care physicians, psychiatrists, psychologists, oncologists, surgeons, and family physicians [including members of the Provincial Palliative Care Committee and the Provincial Psychosocial Oncology Committee]). The survey consisted of items evaluating the methods, results, and interpretive summary used to inform the draft recommendations and whether the draft recommendations should be approved as a guideline. Written comments were invited. The survey was mailed out on October 29, 2007. Follow-up reminders were sent at two weeks (post card) and four weeks (complete package mailed again). The Provider-Patient Communications Working Group reviewed the results of the survey.

Results

Thirty-three responses were received out of the 110 surveys sent (30% response rate). Responses include returned completed surveys as well as phone, fax, and email responses. Of the participants who responded, thirty-one indicated that the report was relevant to their practice or organizational position, and they completed the survey. Key results of the feedback survey are summarized in Table 1.

		Number (%)	
Item	Strongly	Neither	Strongly
	agree or	agree nor	disagree or
	agree	disagree	disagree
The rationale for developing a guideline, as stated in the	25 (82.5%)	0	4 (13%)
"Introduction" section of the report, is clear.			
There is a need for a guideline on this topic.	27 (87%)	1 (3%)	3 (10%)
The literature search is relevant and complete.	26 (84%)	4 (13%)	0
The results of the trials described in the report are	26 (84%)	2 (6.5%)	1 (3%)
interpreted according to my understanding of the data.			· ·
The draft recommendations in the report are clear.	28 (90.5%)	0	2 (6.5%)
I agree with the draft recommendations as stated.	27 (87%)	1 (3%)	3 (10%)
This report should be approved as a practice guideline.	28 (90.5%)	2 (6.5%)	2 (6.5%)
	Very likely	Unsure	Not at all
If this report were to become a practice guideline, how	or likely		likely or
likely would you be to make use of it in your own practice?			unlikely
	26 (84%)	2 (6.5%)	1 (3%)

Table 1. Responses to eight items on the feedback survey.

Summary of Written Comments

Twenty respondents (61%) provided written comments. The main points contained in the written comments were the following (italicized), with the responses from the Working Group:

- 1. A few respondents thought that the term "tactics" in the recommendations should be replaced with "approaches." The Working Group agreed and changed the wording.
- 2. Should state that it's best to use professional translation services and not hospital staff, family or volunteers to translate important information. The Working Group added a statement that the use of professional translation services is recommended.
- 3. More information should be included regarding meeting cultural diversity of patients. Recommendations were added about the provider being culturally sensitive and about considering the patient's ability to communicate in English.
- 4. Conversations about disease progression need to begin sooner than when the transition to end of life care begins. In the recommendations, the Working Group changed from the term 'end of life' to 'disease progression'.
- 5. A more succinct version of the recommendations would be useful. The Working Group created a 10-point summary of important elements to consider when communicating with patients and added it in "Appendix 2: Ten key points for provider-patient communication."

Conclusion

This report reflects the integration of feedback obtained through the external review process with final approval given by the PEBC Provider-Patient Communications Working Group. Updates of the report will be conducted as new evidence informing the question of interest emerges.

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