

Clinical Correspondence

Initial phases in the development of a European Organisation for Research and Treatment of Cancer communication-specific module

Juan Ignacio Arraras^{1*}, Karin Kuljanic², Monika Sztankay^{3,4}, Lisa M. Wintner⁴, Anna Costantini⁵, Wei-Chu Chie⁶, Astrid Helene Liavaag⁷, Eva Greimel⁸, Anne Bredart⁹, Maria Arnott^{10†}, Teresa Young¹¹ and Michael Koller¹²

¹Oncology Departments, Complejo Hospitalario de Navarra, Pamplona, Spain

²Department of Gynecology and Obstetrics, University Hospital Center Rijeka, Rijeka, Croatia

³Department of Psychiatry and Psychotherapy, Innsbruck Medical University, Innsbruck, Austria

⁴Leopold-Franzens-University Innsbruck, Innsbruck, Austria

⁵Psycho-oncology Unit, Sant'Andrea Hospital, Faculty of Medicine and Psychology, Sapienza University, Rome, Italy

⁶Institute of Epidemiology and Preventive Medicine, Department of Public Health, College of Public Health, National Taiwan University, Taipei, Taiwan

⁷Department of Gynecology and Obstetrics, Sørlandets Hospital HF, Arendal, Norway

⁸Medical University Graz, Graz, Austria

⁹Institut Curie, Paris, France

¹⁰EORTC Quality of Life Unit, Brussels, Belgium

¹¹Mount Vernon Hospital, London, UK

¹²University Hospital Regensburg, Regensburg, Germany

*Correspondence to:

Oncology Departments,
Complejo Hospitalario de
Navarra, Irunlarrea 3, 31008,
Pamplona, Spain. E-mail:
jiarraras@correo.cop.es

Received: 21 August 2013

Revised: 11 April 2014

Accepted: 15 May 2014

†On behalf of the EORTC Quality of Life Group

Dear Editor,

Introduction

Communication between patient and professional is a key element in the support offered to *cancer* patients [1,2], especially those with advanced disease. Adequate information disclosure, particularly when receiving bad news, involves a process in which communication is very important [3].

Models of care indicate the type of relationship and communication that is established between the patient and the professional. In recent years, the care given to cancer patients has changed from being *paternalistic* to *patient centered* and on the basis of patient autonomy. The *paternalistic model* is an asymmetrical relationship with the professional occupying the dominant position and the patient merely cooperating. Professionals employ tight interviewing methods to elicit the necessary medical information while providing little opportunity for patients to participate [4]. *Patient-centered cancer care*, on the other hand, respects and responds to the individual patient's

preferences, needs, and values allowing for flexibility in the relations between patients and professionals [5].

The concept of *patient-centered cancer care* includes *patient-centered communication* (PCC), which is defined in terms of processes and outcomes of the patients and clinician interaction [6]:

1. Eliciting, understanding, and validating the patients' perspective (representations, concerns, feelings, etc.);
2. Understanding patients within their own psychological and social contexts;
3. Reaching a shared understanding of patient's problems and how to treat them; and
4. Helping patients share power by offering them meaningful involvement in health-related choices.

Within the PCC model, Epstein *et al.* [6] suggest the following six core functions: fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, making decisions, and enabling patient self-management. These authors understand

that PCC model may contribute to care outcomes and patients' health.

Cross-cultural differences exist in the communication between patients and professionals [7]. In some cultures, patients play a more active role. Such differences may be related to the model of care, and in areas where these are changing, such as Southern Europe, this may influence communication.

Assessing the need for a new communication questionnaire

A critical issue in empirically investigating communication is the availability of an appropriate assessment instrument. Hack *et al.* [8] and Epstein *et al.* [9] recommend that such instruments should assess PCC behaviors – a view endorsed by our group. As an initial step, questionnaires designed to evaluate communication and administered to cancer patients were reviewed (see literature searches). From them, 10 questionnaires developed following a structured process to assess several dimensions of communication were identified. Although each instrument had its merits, no instruments satisfied all four of the following criteria: (i) cancer specific; (ii) developed in a cross-cultural setting; (iii) take account of cross-cultural differences; and (iv) evaluate the different domains of communication between patients and professionals in a PCC model. Thus, we decided that the development of a cancer-specific communication module was called for, following the rigorous development and translation standards of the European Organisation for Research and Treatment of Cancer (EORTC).

Purpose of the module

The aim is to create a specific patient reported outcomes communication questionnaire for cancer patients. This instrument could be used alone, or it could be combined with the generic EORTC Quality of Life questionnaire (QLQ-C30). It should evaluate different dimensions of cancer patients' communications with professionals (doctors, nurses, radiotherapy technicians, etc.) on the basis of the PCC model [6,8,9]. Most of the module's content will concentrate on the professionals' behaviors, including those related to information disclosure. It will be suitable for patients with tumors at any site, and at any disease and treatment stage, including palliative care. Cross-cultural aspects will play a key role in the development of the module. The questionnaire could be used in clinical trials, cross-cultural research, daily practice, and clinical studies.

Methods

The development of the communication module is based on the EORTC Quality of Life Group (QLG) module development guidelines [10], which include four phases. This article covers phases I and II:

1. A review of the literature, to identify an exhaustive list of relevant issues pertaining to the communication between patients and professionals;

2. Modification of this list of issues based on the views and scores of patients in different stages of disease and treatment and of professionals with expertise in this area;
3. Construction of a provisional list of issues for inclusion in the module; and
4. Transformation of the issues list into questionnaire items.

Ethics committee approvals were obtained from all participating countries.

Literature searches were conducted for the period January 2003 to October 2010 in the PUBMED (terms *cancer and communication* and *questionnaire*) and PSYCHINFO (*cancer and communication*) databases.

Studies presenting instruments to evaluate communication as a general questionnaire or as part of a questionnaire plus other communication assessment modalities such as observing codes were selected and reviewed. Questionnaire databases were reviewed (PROQOLID, BIBLIOPRO, and the FACIT system). In all these cases, instruments had been created for cancer patients or used in studies with cancer patients. Studies focusing on other areas of the communication with cancer patients, like the training of profes-

Table I. Demographic and clinical characteristics of the sample

	Frequency (N=41)	%	Mean	SD
Age (range 28–76 years)			51.2	12.2
Sex				
Female	24	58.5		
Male	17	41.5		
Level of education				
Less than compulsory	4	9.7		
Compulsory	10	24.4		
Post-compulsory university	15	36.6		
University level	12	29.3		
Countries				
Austria	4	9.7		
Croatia	10	24.4		
Italy	10	24.4		
Spain	17	41.5		
Disease location				
Breast	12	29.3		
Colorectal	6	14.6		
Head and neck	6	14.6		
Ovarian	6	14.6		
Lung	3	7.3		
Pancreatic	2	4.9		
Other sites	6	14.0		
Disease stage				
Local/locoregional	20	48.8		
Metastatic	21	51.2		
Treatment stage				
Initial	9	21.9		
During	18	43.9		
Follow-up	11	26.8		
Palliative care	3	7.4		
Surgery	20	48.8		
Radiotherapy	19	46.4		
Hormone therapy	7	17.1		
Chemotherapy	22	53.7		

Table 2. Provisional list of issues

Provisional list of issues organized in areas and scales
Area 1 Scale 1. Patient's active role: behaviors
1. Patient considers he/she has enough opportunities to participate
2. Patient feels free to ask questions
3. Patient expresses emotions, worries, and so on
4. Patient expresses needs
Area 2 Aspects of the clinician–patient relationship.
Scale 2: Therapeutic alliance, interaction, and time
5. Professional and patient share their understanding of the disease and treatment
6. Mutual trust between professional and patient
7. Mutual respect between professional and patient
8. Professional takes enough time to talk to the patient
9. Professional takes enough time for patient to ask questions and to reply to them
Scale 3. The professional's qualities in creating a relationship
10. Professional approaches the patient equally
11. Professional shows sincerity
12. Professional makes the patient feel relaxed or comfortable and helps the patient to talk openly about everything, ask questions, and express his or her comments and feelings openly
13. Professional treats the patient with respect
14. Professional takes the patient's problems seriously
Scale 4. The professional's skills
15. Professional uses a language that the patient understands (overcoming barriers of low literacy, avoiding medical jargons, and using clear terms)
16. Professional answers questions openly
17. Professional makes eye contact
18. Professional uses a calm voice (slows down verbal communication)
Area 3 Scale 5. Management of patient's emotions
19. Professional recognizes the emotions
20. Professional tries to understand the patient's situation
21. Professional understands the patient's knowledge and perspective of the disease, the treatment and the situation
22. Professional listens
23. Professional offers counseling about possible disturbances
24. Professional manages negative emotions: sadness, anger, fear, etc.
Area 4 Scale 6
25. Attention to patient information preferences and needs on information
Area 5 Scale 7. Information: ** communication skills related to information
26. Professional checks what the patient already knows about the illness to start giving information from this level
27. Professional checks understanding of the information and repairs misunderstandings
28. Professional shows ability to answer difficult questions (prognosis, etc.)
29. Professional shows ability to discuss honestly the goal of the treatment (cure, etc.)
30. Professional shows ability to give hope and to give faith in the treatment with honesty
Area 6 Scale 8. The environment where the communication occurs
31. There is intimacy (a private room) to have confidential conversations with professionals
32. There is a lack of disturbance or interruptions during the sessions with professional and with carers (e-mails, phones, etc.)
Area 7 Scale 9
33. Satisfaction with communication

We propose dividing the issues into seven areas of content and nine scales (area two will have three scales).

sionals, were also selected and reviewed. Studies from experts in the field of communication in oncology that had not been found in this search were also evaluated, as were studies identified in the papers found in this first previous search. This second group of papers could have been published before or after 2003.

Results

A total of 204 papers and 79 instruments were selected. Of the 79 instruments, 53 were developed according to a well-established system, and 26 were study specific. Some

instruments assessed several dimensions, whereas others focused on just one dimension of communication, for example, empathy.

An initial list of 320 issues was constructed after the review of the literature. This list of issues was reduced in several steps following the guidelines [10]. In accordance with the aims of the module and the first four functions of the PCC model, areas that could be included in the communication questionnaire, and the issues that fitted into these areas, were selected. Some areas, such as decision making, enabling patient self-management, contents of the information offered, or end-of-life communication, were excluded,

as they required a specific instrument. Besides, some specific criteria (e.g. redundancy and too technical) were considered to reduce issues to 68 before the patients' interviews.

Patient and professional interviews: three steps

Semi-structured interviews were conducted with 23 patients from Austria, Croatia, Italy, and Spain. Open questions enquired about areas of communication between patients and professionals that our group had considered important. After these interviews, five new issues were added to the list, which then comprised 73 issues.

Interviews were conducted with professionals

Twenty-three professionals from Austria, Croatia, Norway, Spain, and Taiwan (three oncologists, two gynecologists and a family medicine doctor, three radiation therapy technicians, four psycho-oncologists, seven nurses, and three other health professionals) were interviewed. Professionals were asked to evaluate the level of relevance for each of the 73 issues (1–4), to select the 25 most important issues and say whether they considered that there were any other issues related to communication that were not included in the provisional list.

A *second round of patient interviews* was conducted with 18 new patients from Austria, Croatia, Italy, and Spain. These patients had the same instructions as the professionals. Patients from both rounds of interviews were organized in seven subgroups. Six of these subgroups were based on a combination of disease stage (initial and advanced) and treatment stage (initial, during, and after). There was a seventh subgroup for patients who were receiving palliative care.

In total, 41 patients participated in the two rounds of interviews. Their sociodemographic and clinical data are shown in (Table 1). There was a good representation of disease sites and treatment modalities.

The provisional list of issues was reduced on the basis of the relevance and importance scores of patients and professionals, with special attention paid to the opinions of the patients and to the importance scores (50% of patients and/or professionals considered the issue as important). Of the issues, 33 were selected and provisionally divided into seven areas of content presented in nine scales (Table 2).

Operationalization: construction of the provisional module

The list of issues was operationalized into questions consistent with existing EORTC QLG modules. No items were copied from other instruments. The word *cancer* was not included because this could be intrusive for patients who

had not openly received their diagnosis. Instructions invite the respondent to indicate the professional category (doctors, nurses, psychologists, radiotherapy technicians, etc.), and specific treatment period (diagnoses, treatment, and follow-up) that the module is addressing in each study.

Consultation of health care professionals

The resulting provisional list of items was reviewed for clarity and overlap by French and Spanish health care professionals. The content was considered adequate.

Conclusions

This manuscript presents phases I and II of the EORTC QLG module development process. We consider the strengths of the project to be the literature review and that patients, professionals, and researchers from different cultural areas have been involved.

The provisional module is being tested in a phase III study, and additional cultural areas will be involved. Phase III will identify and solve practical problems relating to the administration of the questionnaire and aspects of its cross-cultural application and determine whether additional items are needed or whether existing ones should be removed. Once completed, we will have a robust instrument for use in both clinical work and cross-cultural studies.

Acknowledgements

The study was supported by grants from Departamento de Salud del Gobierno de Navarra and the Caja de Ahorros de Navarra, Spain. The work of M. S. and L. M. W. was supported by the Austrian National Bank.

Key points

- Communication between patient and professionals is a key element in the support offered to patients.
- A team from the EORTC QLG is developing a questionnaire to evaluate the different dimensions of patients' communication with professionals.
- This manuscript presents phases I and II of the development process, including a review of the literature, two rounds of patient interviews, one round of professional interviews, and a formulation of the items.
- Cross-cultural differences play a key role in communication: to take this into account, all these steps have been carried out in different countries simultaneously.
- A provisional module to be tested in a patient population with various cultural backgrounds has been created.

References

1. Ansmann L, Kowalski C, Ernstmann N, Ommen O, Pfaff H. Patients' perceived support from physicians and the role of hospital characteristics. *International J Qual Health Care* 2012;24(5):501–508.
2. Carlson LE, Feldman-Stewart D, Tishelman C, Brundage MD, SCRIN Communication Team. Patient-professional communication research in cancer: an integrative review of research methods in the context of a conceptual framework. *Psycho-Oncology* 2005;14(10):812–828.

3. Fallowfield L, Jenkins V. Communicating sad, bad, and difficult news in medicine. *Lancet* 2004;**363**:312–319.
4. Morgan M. The doctor–patient relationship. In *Sociology as Applied to Medicine*, Scambler G (ed.), Saunders/Elsevier: Edinburgh, New York, 2008; 49–65.
5. Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. National Academy Press: Washington, DC, 2001.
6. Epstein RM, Street RL Jr. *Patient-centered Communication in Cancer Care: Promoting Healing and Reducing Suffering*. National Cancer Institute: Bethesda, MD, USA, 2007.
7. Surbone A. Cultural aspects of communication in cancer care. *Support Care Cancer* 2008;**16**(3):235–240.
8. Hack TF, Degner LF, Parker PA, SCRN Communication Team. The communication goals and needs of cancer patients: a review. *Psycho-Oncology* 2005;**14**(10):831–845.
9. Epstein RM, Franks P, Fiscella F, et al. Measuring patient-centered communication in patient–physician consultations: theoretical and practical issues. *Soc Sci Med* 2005;**61**:1516–1528.
10. Johnson C, Aaronson N, Blazeby J, et al. *EORTC Quality of Life Group Module Development Guidelines (4th edn.)*, EORTC QL Group: Brussels, 2011.