EVALUATION OF AWARENESS OF INCURABLE DISEASE (AID): CREATION, REVIEW AND PILOT TESTING OF CLINICAL TOOL

by

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Glossary

AID	Assessment of incurable disease
AOPSS	Ambulatory Oncology Patient Satisfaction Survey
EORTC	European Organization for Research and Treatment of Cancer
I-PSS	International Prostate Symptom Score
KPS	Karnofsky Performance Status
MUHC	McGill University Health Center
NCCN	National Comprehensive Cancer Network
PAS	Patient acceptability survey
PMH	Past medical history
QoL	Quality of life
RTOG	Radiation Therapy Oncology Group

Abstract

Introduction:

Communication of distressing news such as metastatic cancer is challenging for patients and doctors. During the course of their care, 60% of patients diagnosed with cancer will receive a palliative treatment, and it is not clear if patients understand the goals of treatment and the incurable nature of their cancer at that stage. Our goal was to design a simple questionnaire to assess, in a rapid manner, if patients with metastatic cancer are aware of the extent and prognosis of their disease.

Methods:

The first phase was a review of the literature, including 25 validated questionnaires used in clinical practice, to create a draft with questions related to the extent and prognosis of cancer. The second phase included a review of the draft with 30 healthcare professionals with experience in oncology, including oncologists, palliative care doctors, psychologists and nurses where the questionnaire was finalized. The third and last phase was the pilot testing of the questionnaire in clinical practice to assess feasibility and acceptability. Patients with metastatic cancer and referred for palliative radiation were randomly chosen to receive the questionnaire before the consultation. The data obtained from the questionnaire, acceptability survey and patients' characteristics were gathered for analysis.

Results:

27 patients were included for the pilot testing of the questionnaire. Mean age was 68; 62% were male; mean KPS 80; median time since metastatic disease was 10.6 months. Most common primary tumor was lung (48%). 19 (70%) patients preferred all, 7 (26%) preferred limited and 1 (4%) no information. 18 patients (69%) believed the goal of the treatment was to cure their cancer and for only 8 (31%) it was clear that the treatment was to palliate symptoms, but not for cure. 6 (22%) patients believed their cancer was still limited to the primary organ. 9 (33%) patients believed their current treatment was to prolong their survival for more than one year. 95% of the patients were comfortable to answer the questionnaire, and didn't consider it a burden. 90% found it helpful to obtain information about their prognosis. Doctors reported a facilitated discussion and no distress associated to the questionnaire.

Conclusion:

The proposed questionnaire is simple, seems acceptable to patients without causing distress, and facilitated discussion between patients and doctors. Most patients with metastatic cancer referred for palliative radiation did not report having incurable cancer, which could contribute to unrealistic expectations. Further research is warranted to confirm these findings, understand and explain them.

Abstract (French)

Introduction:

La communication de mauvaises nouvelles, telle que le diagnostic d'un cancer métastatique, est difficile pour les patients et les médecins. Durant leurs soins, 60% des patients diagnostiqués avec un cancer recevront un traitement palliatif et il n'est pas clair si les patients comprennent l'objectif des traitements et la nature incurable de leur cancer à ce stage. Notre objectif était de créer un questionnaire simple pour une évaluation rapide de la compréhension des patients de l'étendue et du pronostic de leur maladie.

Méthodes:

La première phase était une revue de la littérature, comprenant 25 questionnaires validés utilisés dans la pratique clinique, pour créer une ébauche avec des questions liées à l'étendue et le pronostic du cancer. La deuxième phase comprenait une revue de l'ébauche avec 30 professionnels de la santé ayant une expérience en oncologie, y compris des oncologues, des médecins en soins palliatifs, des psychologues et des infirmières, puis la finalisation du questionnaire. La troisième et dernière phase était l'essai pilote du questionnaire en pratique clinique pour évaluer la faisabilité et l'acceptabilité. Les patients avec un cancer métastatique et référés pour une radiothérapie palliative ont été choisi aléatoirement pour recevoir le questionnaire avant la consultation. Les données obtenues à partir du questionnaire, du sondage d'acceptabilité et des caractéristiques des patients ont été recueillies pour l'analyse.

Résultats:

27 patients ont été inclus pour l'essai pilote du questionnaire. L'âge moyen était de 68 ans; 62% étaient des hommes; moyenne KPS 80; temps médian depuis le diagnostic de maladie métastatique était de 10,6 mois. La tumeur primitive la plus fréquente était le poumon (48%). 19 (70%) patients ont préféré toutes les informations, 7 (26%) ont préféré certaines et 1 (4%) aucune information. 18 patients (69%) croyaient que le but du traitement était de guérir leur cancer et pour seulement 8 (31%) il était clair que le traitement était de pallier les symptômes, mais pas de guérir. 6 (22%) des patients pensaient que leur cancer était encore limité à l'organe primaire. 9 (33%) des patients pensaient que leur traitement actuel consistait à prolonger leur survie pendant plus d'un an. 95% des patients étaient à l'aise à répondre au questionnaire et ne l'ont pas considéré comme un fardeau. 90% l'ont trouvé utile pour obtenir des informations sur leur pronostic. Les médecins ont signalé une discussion facilitée et aucune détresse associée au questionnaire.

Conclusion:

Le questionnaire suggéré est simple, semble acceptable pour les patients sans causer de détresse, et facilite la discussion entre les patients et les médecins. La plupart des patients atteints de cancer métastatique référés pour une radiothérapie palliative n'ont pas déclaré avoir un cancer incurable, ce qui pourrait contribuer à des attentes irréalistes. D'autres recherches sont nécessaires pour confirmer ces constatations, les comprendre et les expliquer.

Preface and Contribution of Authors

All the work presented was conducted at the McGill University Health Center (MUHC). The project was approved by the MUHC Research Ethics Board.

None of the chapters were published. I was responsible, under the supervisor of Dr. Sergio Faria throughout the project, for identification and design of the research, review of the literature, data collection, data analysis, and preparation of the thesis.

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Acknowledgements

I had the pleasure to pursue this research under the supervision of Dr. Sergio Faria. I am thankful for his guidance, his input, his advice, his vision of science and his dedication to improve information translation from healthcare professionals to patients. I learned a lot on the subtleties of information translation during this research project, and this would not have been possible without his support.

I also acknowledge the collaboration of the research meeting committee and the healthcare professionals, including physicians, nurses and allied professionals, that shared their experience and their assistance in reviewing the questionnaire. I am grateful for their help and support throughout this project.

CHAPTER 1 Introduction

Communication of distressing news can be demanding for both doctors and patients [1] [2] [3]. The question is not whether to tell or not the patients the bad prognosis and the incurable state of their cancer, but in more recent times, the debate has focused on the amount of information to give and mostly how to convey it [4] [5]. Although disclosing a cancer diagnosis is more common practice now [6], there is a wide variability amongst physicians in regards to disclosing or discussing prognosis [7] [8]. Disclosure of a diagnosis of incurable cancer has been identified by both clinicians and patients as an important and contentious issue [9] [10].

Healthcare professionals including doctors are aware of their responsibility to ensure a clear understanding of cancer and its important role in care planning and realistic goal setting [11] [12]. However, multiple physicians also believe that discussing incurable disease correlates to “giving a death sentence” and are aware that a subset of patients might not want to discuss a bad prognosis [13] [14]. Oncologists described their feeling during these conversations as “unhappy,” “unpleasant,” “frustrating,” “bothersome,” “difficult,” “hard,” “exhausting,” and “draining” [15] [16]. Given these beliefs, it is no surprise that doctor’s behaviors in disclosing information about the disease and prognosis vary widely [17] [18].

During the advanced metastatic phase of the disease, treatment decisions can be complex and involve consideration of questionable clinical trials, futile treatments, and challenges of sustaining hope and having realistic goals [19] [20]. These treatment options are growing in an era of individualized medicine and patient engagement [21] – highlighting the importance of assessing the understanding of patients with incurable cancer. Appropriate personalized medical decisions can be made with appropriate understanding of the patient about his or her metastatic cancer. With the increase of digital information on the internet and social medias, there is also countless erroneous sources of information consumed that guide to falsehoods and stimulate fears and anxieties [22]. Healthcare professionals have the responsibility to correct any misinformation, and this educational role cannot be done without a screening tool for false beliefs about cancer.

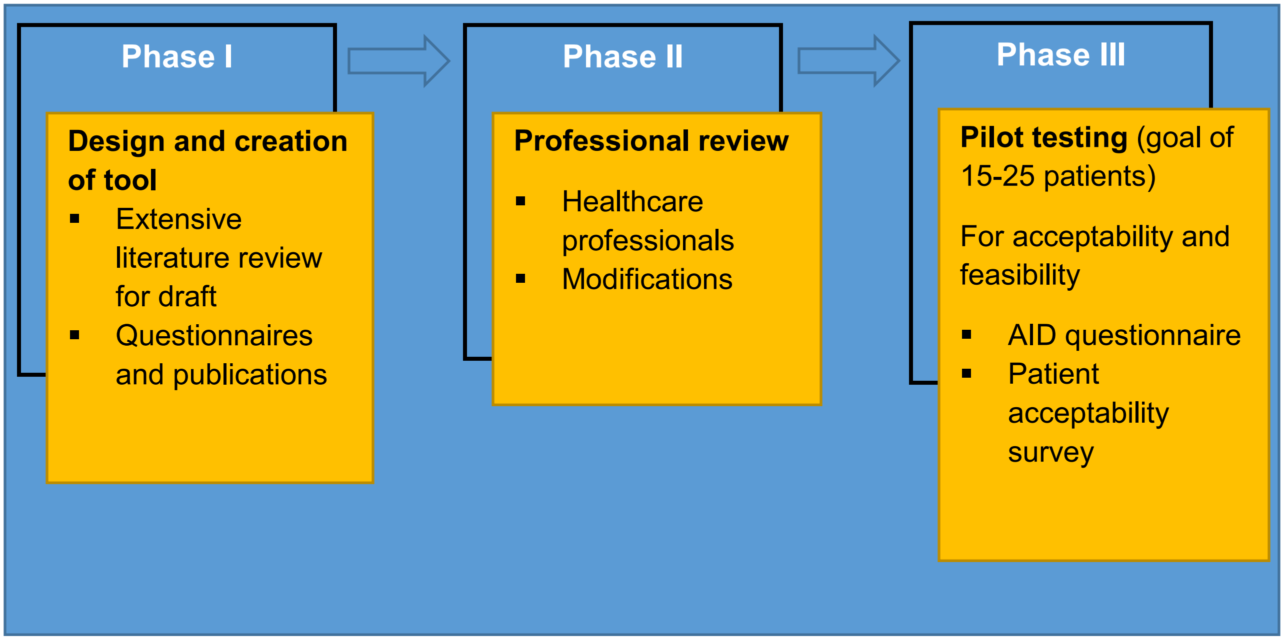
During the course of their care, 60% of patients diagnosed with cancer will have spreading of their disease and become incurable [23] [24]. In Departments of Radiation Oncology, it is estimated that 25 to 50% of patients seen for treatment have metastatic disease [25], and especially in the Division of Radiation Oncology at the MUHC where the proportion of patients with metastatic cancer is 47% [26]. During the advanced phase of the disease, patients are seen and treated by many physicians. It is difficult to know what is being told to the patient and what is his or her understanding of the whole clinical situation and prognosis [27] [28].

With regards to patient understanding of their advanced cancer, the awareness ranged from 0 to 75% based on a systematic review [29]. This wide variation can lead to potential misunderstandings between healthcare professionals and patients about the disease [30]. Dissatisfaction of patients for doctors' explanations and communication was found to have a negative impact on the perception of the care received, even when the quality of care followed the most updated guidelines. In the Ambulatory Oncology Patient Satisfaction Survey (AOPSS) for 2013, the Rossy Cancer Network average score for the domain of "Information, Communication & Education" was low with 74.8%, slightly below the Canadian average [31]. Thus, using a standardized approach such as a simple one-page questionnaire can help different healthcare professionals to rapidly obtain information on patient understanding of having an incurable cancer and lessen confusion about the goals of care and of management. The questionnaire will be called AID – awareness of incurable disease.

Although it is common for patients to wait for the doctor to initiate a conversation about treatment and prognosis [32], patient fears and limited resources such as inadequate consultation time, frequent interruptions, insufficient privacy can act as barriers to effective communication [29] [33] [34]. There is also evidence that accurate prognostic awareness can relate to reduced psychological distress and improved quality of life [35] [36]. To our knowledge, there is no tool in the literature at the moment to use in clinical setting to assess the understanding of a patient on his or her disease extent and the diagnosis of incurable cancer [37].

The present project addresses the need to develop such clinical tool to assess the understanding among patients with advanced incurable cancer of their poor prognosis.

Our research project's design is shown in Figure 1 – Proposed design.



Our goal was to create and design a brief, simple and useful self-administered tool for screening patient information preferences and understanding of cancer extent, to facilitate and stimulate discussions, to allow patients to obtain the information desired for their decisions, to improve the patient-healthcare professional relationship, and to maintain a sensitive approach to sustaining hope, without causing distress, and setting realistic goals.

Awareness of having an incurable cancer is important for patients to set goals and priorities and make decisions about their medical care and treatments. Having a respectful and sensitive discussion that includes mutual understanding of prognosis can be stressful but if done well, can lead to a true patient-centered dialogue.

Keywords: information, patients, understanding, questionnaire, quality of life, diagnosis, prognosis, metastatic, incurable, acceptability, palliative, preferences

CHAPTER 2 Phase I: Comprehensive Literature Review

The **first phase of the project was to review the literature and existing questionnaires used in daily practice.** The aim of this phase was to generate items related to patient quality of life (QoL), reporting of symptoms, and awareness of disease. An extensive and systematic review was conducted using PubMed, OvidSP and Psychinfo database from 1985 to 2016 to search the literature for articles related to these themes among cancer patients – we included the following terms in our strategic search for questionnaires for the MeSH Major Topics: “incurable cancer” OR “terminal cancer” OR “advance metastases” OR “terminally ill” OR “terminal illness”, AND “prognosis disclosure” OR “prognosis awareness” AND “patient knowledge” OR “patient awareness” OR “patient comprehension” OR “patient understanding” AND “tools” “questionnaires”.

Our search led to 25 available validated questionnaires and a total of 29 publications presented in Table 1. The current questionnaires assess many elements of quality of life, described in the table, including pain, fatigue, sleep, appetite, finances, relationships – but not patient information preferences and understanding of extent and prognosis of cancer disease. Twenty out of the 25 questionnaires contain 10 items or more, and 12 out of 25 had 20 items or more – well above our aim of a short and simple tool containing a handful of items for rapid screening. During this phase, the creation and design of a single-page questionnaire was done according to the literature review. The initial items were generated and we drafted the initial version of the AID questionnaire.

Table 1. Literature review – questionnaires and publications

Tool	Complete name	Elements assessed	Length (questions)	Year published	Ref.
EQ-5D	Measure of health outcome and status	Mobility, self-care, usual activities, pain/discomfort, anxiety/depression	26	1998	[38]
QLQ-C30	Questionnaire to assess quality of life of cancer patients	Activities, fatigue, pain, sleep, appetite, stress, gastrointestinal symptoms	30	1993	[39]
QOLLTI-P	Questionnaire for quality of life in life-threatening illness-patient	Depression, anxiety, financial situation, relationships, quality of health care	25	2013	[40]
QOLLTI-F	Questionnaire for quality of life for family carer	Environment, patient state, carer's state, quality of care, relationships, financial worries	20	2006	[41] [42]
PO-Bado Tool	Basic Documentation for Psycho-Oncology	Fatigue, mood, anxiety, depression, activities	6	2014	[43] [44]
K10	Kessle Psychological Distress Scale	Fatigue, anxiety, anxiety, depression	10	2001	[45]
QSC-R10	Questionnaire on Stress in Cancer Patients	Fatigue, pain, distress, sleep, activities, anxiety	10	2011	[46]
RTOG FACT-G	Functional Assessment of Cancer Therapy-General	Physical, social, emotional, functional well-being	27	1993	[47]
FLIC	Functional Living Index-Cancer	Physical/occupational function, psychological state, social life, somatic discomfort	22	1988	[48] [49]
MQOL	McGill Quality of Life Questionnaire	Physical symptoms, depression, anxiety, meaning of life, support	17	1995	[50]
HUI	Health Utilities Index	VIsion, hearing, ambulation, dexterity, emotion, cognition, pain, speech	21	1995	[51]

I-PSS	International Prostate Symptom Score	Urinary symptoms, quality of life	8	1995	[52]
NCCN Distress Scale	NCCN Distress Scale	Distress, practical/ family/ emotional/ spiritual/ physical problems	40	2016	[53]
EPIC	Expanded Prostate Cancer Index Composite	Urinary symptoms, sexual function, mood, energy, hot flashes	16	2000	[54]
AQoL-8D	Assessment of Quality of Life	Independent living, pain, depression, coping, relationships	35	2014	[55]
BCD	Brief Case-Find for Depression	Mood, sleep, satisfaction	4	2004	[56]
EORTC PR7	Questionnaire for need of incontinence aid	Urinary symptoms, need for incontinence aid	5	2012	[57]
BPI	Measure of Brief Pain Inventory	Pain, activities, mood, work, relations, sleep	15	1994	[58]
HADS	Hospital Anxiety and Depression Scale	Anxiety, worries, fears, panic, sadness	14	2009	[59] [60]
DASS-21	Depression, Anxiety and Stress Scale	Depression, sadness, worthlessness, fears, anxiety, physical symptoms	21	1995	[61]
SF-12	Physical and mental health scales	Health, activities, endurance, pain, mental health, social interactions	12	1996	[62]
SNI	Berkman-Syme Social Network Index	Marital status, children, relatives, friends, employment, communication	12	2003	[63]
NHP	Nottingham Health Profile	Energy level, pain, emotional well-being, sleep, social interactions, physical abilities	38	1985	[64]
SWLS	Satisfaction With Life Scale	Satisfaction with life, life conditions, wants	5	1985	[65]
QLI	The Ferrans and Powers Quality of life Index	Health, functioning, social, economical, psychological, spiritual, family	33	1985	[66]

CHAPTER 3 Phase II: Healthcare Professional Review

The **second phase of the project is the review of the questionnaire with healthcare professionals with experience in cancer care**.

The aim of this phase was to elicit clinician input on which items are relevant to retain from the pool of items drafted in the initial version (relevance), if the right content was included (comprehensive), and to discuss if the items were clear, unambiguous, and phrased appropriately.

30 healthcare professionals specialized in cancer care participated in this review:

- 15 physicians: 12 oncologists, 3 palliative care doctors
- 4 nurses with experience in cancer care
- 2 psychologists and 1 dietitian practicing in a cancer setting
- 8 technologists in radiation oncology, with daily encounters with patients

This phase was done as an individual review for the 30 clinicians, and as a group discussion afterwards with the 12 oncologists. The questionnaire was then modified after each review as shown in Table 2, and adjusted before the subsequent review. The suggested modifications were tailored to the goal of designing a single-page questionnaire to assess awareness of incurable cancer.

Table 2. Major modifications from review

Major modifications
▪ Phrasing of part I
▪ Phrasing of the 4 items
▪ Selecting items tailored for understanding
▪ Combining choices to three - For ease and rapidity
▪ Changing order of questions
▪ Separating part I and II on different pages - To avoid that patients who do not want information read the questions

There were a total of 22 modifications and versions done before the final version. The final questionnaire is shown in Figure 2 and included 2 parts - the first as one question to assess if the patient wants or not information about his cancer now (all, some or none of the information).

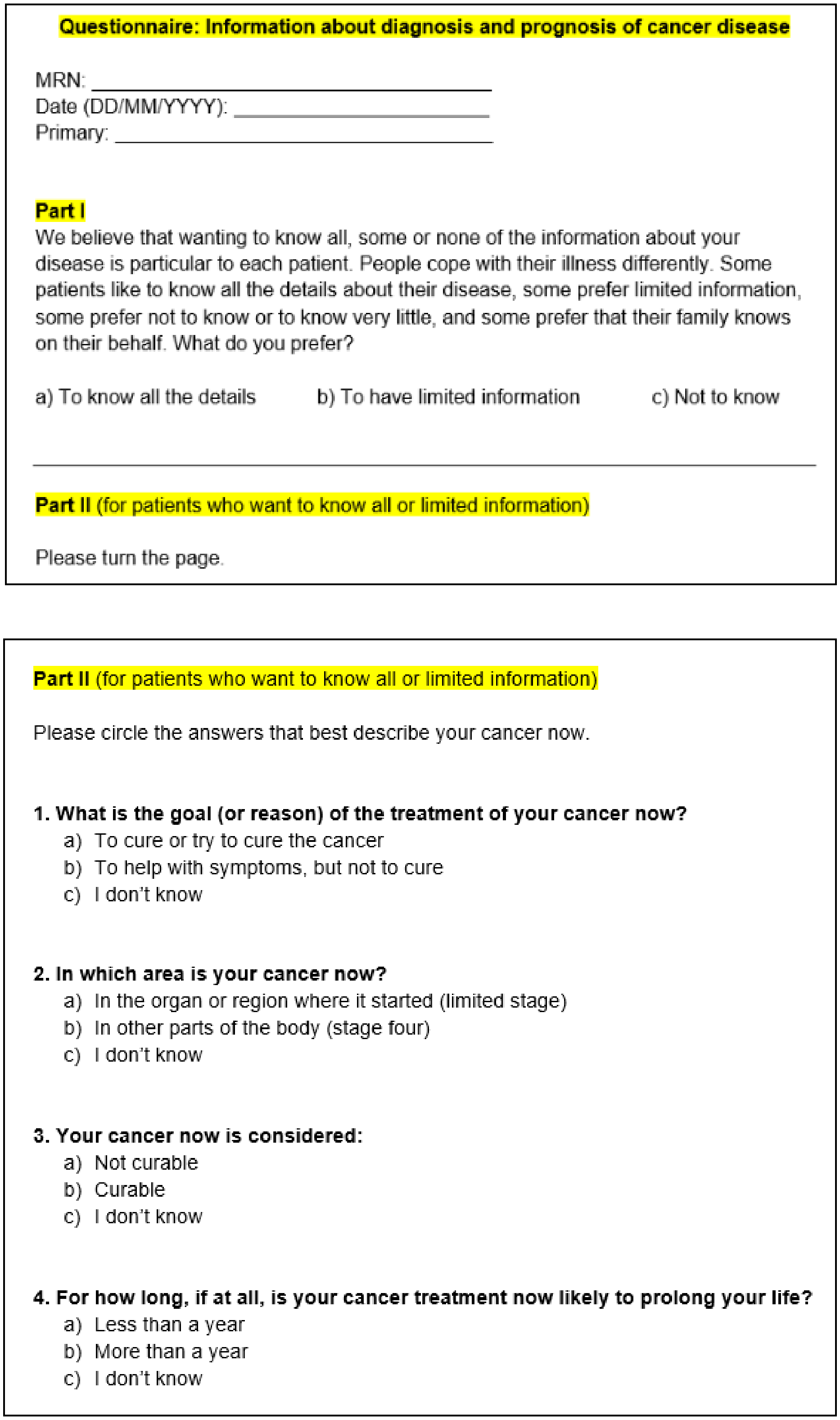
The second part included the four items to assess the understanding of:

- Extent of disease
    - *Question 1: What is the goal (or reason) of the treatment?*
    - *Options: To cure, to help with symptoms, or don't know*
- Treatment intent (palliation or cure)
    - *Question 2: In which area is your cancer now?*

    - *Options: In the organ where it started (limited), in other parts of the body (stage four), or don't know*
- Disease eradication
    - *Question 3: Your cancer now is considered not curable or curable*
    - *Options: Incurable, curable, or don't know*
- Expectancy of survival from the treatments
    - *Question 4: For how long is your treatment likely to prolong your life?*
    - *Options: Less than a year, more than a year, or don't know*

The final list of items was then assessed for reading ease, and adapted for an average grade level of 6th grade for readability using the Flesch-Kincaid Grade Level Index and the Clear Language and Design Effectiveness Tool. This list was then translated in French and reviewed with 10 Francophone patients for comprehension of the items.

Figure 2. AID Questionnaire



Questionnaire: Information about diagnosis and prognosis of cancer disease

MRN: ______________________________
Date (DD/MM/YYYY): ___________________
Primary: ____________________________

Part I

We believe that wanting to know all, some or none of the information about your disease is particular to each patient. People cope with their illness differently. Some patients like to know all the details about their disease, some prefer limited information, some prefer not to know or to know very little, and some prefer that their family knows on their behalf. What do you prefer?

a) To know all the details   b) To have limited information   c) Not to know

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Part II (for patients who want to know all or limited information)

Please turn the page.

Part II (for patients who want to know all or limited information)

Please circle the answers that best describe your cancer now.

1. What is the goal (or reason) of the treatment of your cancer now?
- a) To cure or try to cure the cancer
- b) To help with symptoms, but not to cure
- c) I don't know

2. In which area is your cancer now?
- a) In the organ or region where it started (limited stage)
- b) In other parts of the body (stage four)
- c) I don't know

3. Your cancer now is considered:
- a) Not curable
- b) Curable
- c) I don't know

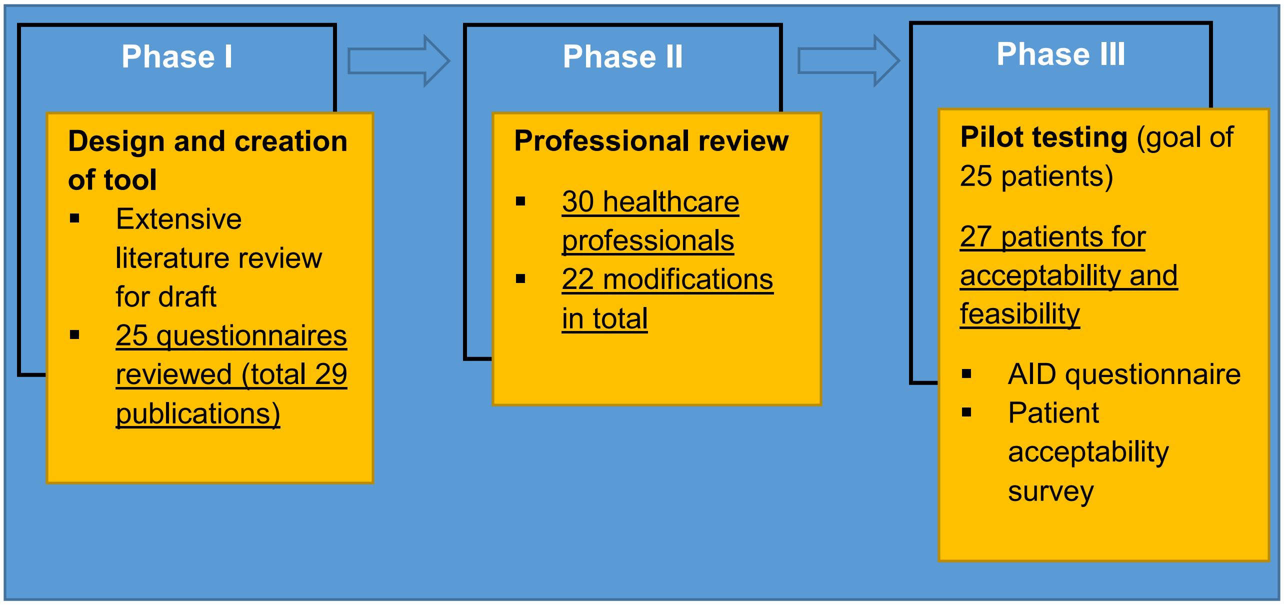
4. For how long, if at all, is your cancer treatment now likely to prolong your life?
- a) Less than a year
- b) More than a year
- c) I don't know

CHAPTER 4 Phase III: Pilot Testing

The **third phase of the project is the pilot testing** of the questionnaire in a clinical setting followed by a survey for acceptability and feasibility.

The final questionnaire was planned to be piloted with 25 patients. This sample was determined according to the literature for qualitative sample size for acceptability and feasibility of questionnaires. The ALERT-B questionnaire, published in Clinical Oncology, to detect chronic gastrointestinal symptoms after pelvic radiation was piloted with 12 patients [67]. The QWLQ questionnaire, published in BMC Health, to assess quality of life in cancer survivors was piloted with 19 patients [68]. The questionnaire for adherence to capecitabine, published in Bull Cancer, was piloted with 15 patients [69].

Figure 3. Research design



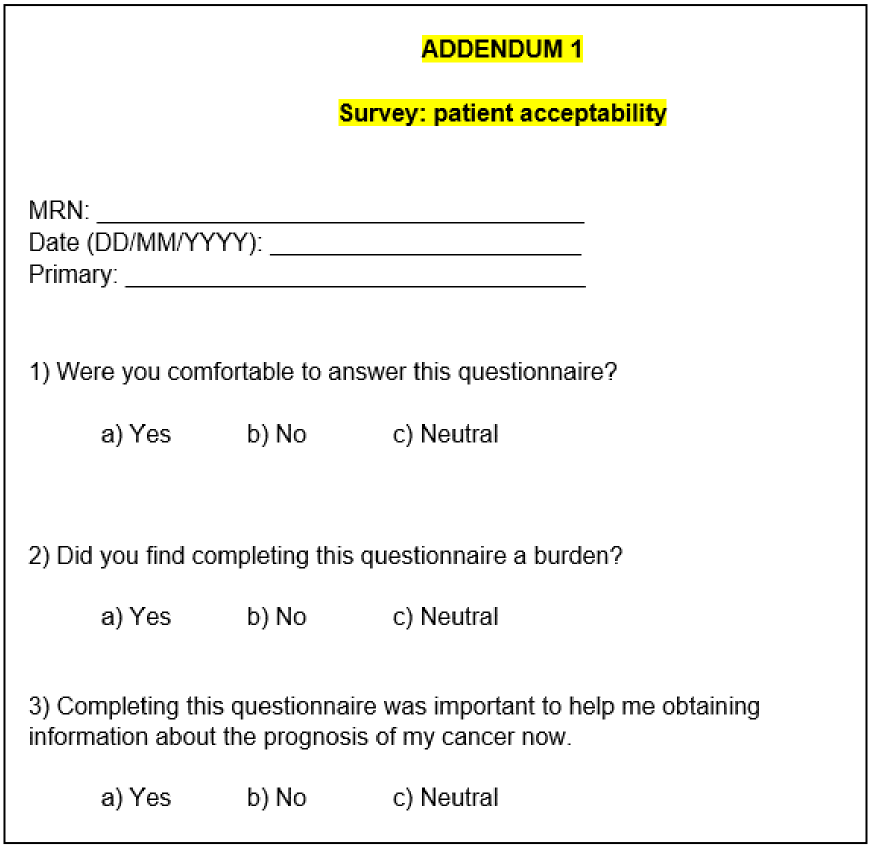
All patients included in the pilot test had a diagnosis of metastatic cancer, were 18 years or older, and were referred for palliative treatment in the Division of Radiation Oncology at the MUHC, and able to communicate in English or French.

Table 2 summarizes the steps followed in the third phase. First, at the reception, eligible patients were given the questionnaire before the consultation. If the patient responded that he or she wanted to have all or partial information about the cancer, he or she received the part 2 with the four described items, shown in Figure 2. The completed questionnaire was then given to the treating clinician before the consultation as a guide to understand the patient information comprehension about the cancer. Then, the patients had the chance to discuss their questions and concerns during the consultation. At the end of the consultation, the patient received and completed the acceptability survey once the doctor had left.

Table 3. Distribution of questionnaire and PAS

Order	Methods
1	Distribute questionnaire to patient respecting inclusion criteria
2	Provide completed questionnaire to doctor
3	Allow patient to discuss questions and concerns
4	Provide patient acceptability survey after the consultation

Figure 4. Patient acceptability survey



ADDENDUM 1

Survey: patient acceptability

MRN: ______________________________
Date (DD/MM/YYYY): ___________________
Primary: ____________________________

1) Were you comfortable to answer this questionnaire?

a) Yes b) No c) Neutral

2) Did you find completing this questionnaire a burden?

a) Yes b) No c) Neutral

3) Completing this questionnaire was important to help me obtaining information about the prognosis of my cancer now.

a) Yes b) No c) Neutral

The patient acceptability survey is shown in Figure 2. The goal of the survey is to assess if the questionnaire is:

- Acceptable to patients and if it caused distress
    - *Question 1: were you comfortable to answer this questionnaire?*
- Burdensome
    - *Question 2: did you find completing the questionnaire a burden?*
- Helpful to stimulate discussions and obtaining information about their cancer
    - *Question 3: completing the questionnaire was important to help me obtaining information about the prognosis of my cancer now*

This survey was adapted from the Patient experience measure used in the province of Ontario [70], and a combination of four validated surveys:

- Patient Perception of Patient Centredness [71]
- Patient Activation Measure [72]
- Self-Efficacy for Management of Chronic Disease [73]
- Care Provider Emotional Support [74].

The data obtained from the questionnaire, acceptability survey and patients' characteristics were gathered for analysis. Following the survey, the input from clinicians was gathered after the consultation to understand whether and how the tool influenced the consultation and interactions with the patient.

Patients' characteristics included age, gender, marital status, ethnic origin, education level, occupation or previous occupation, psychiatric past medical history, performance status, time since diagnosis of metastases, cancer type, metastatic tumor sites, current treatment site, and prior treatments, as shown in Table 4.

Table 4. Patients characteristics

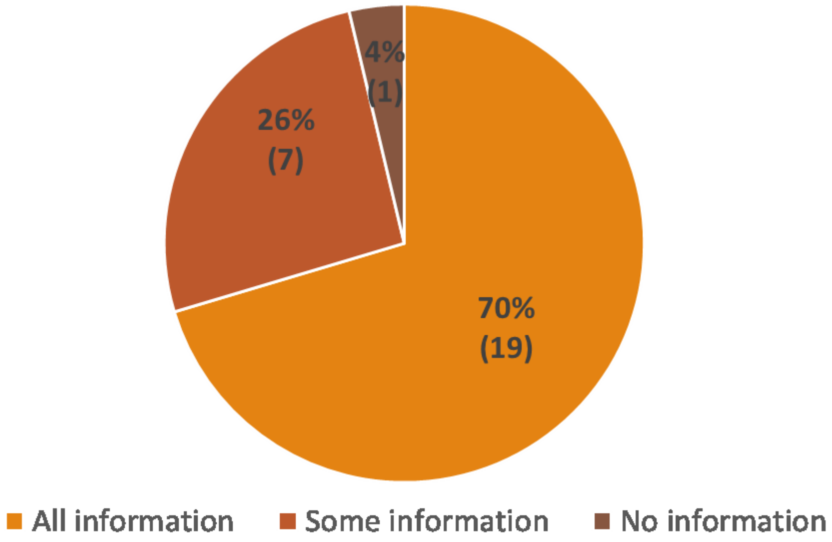
PATIENTS CHARACTERISTICS	VALUES	RANGE
Age (mean in years)	68.14 (95% CI: 63.34-72.94)	40-92
Gender	▪ Male: 62% ▪ Female: 38%	-
Marital status	▪ Single: 14% ▪ Married: 52% ▪ Widowed: 34%	-
Ethnic origin	▪ French Canadian: 60% ▪ English Canadian: 10% ▪ Other: 30%	-
Number of children	▪ None: 19% ▪ One-two: 62% ▪ Three-four: 10% ▪ Five +: 9%	-
Education	▪ Primary: 10% ▪ High school: 57% ▪ University: 33%	-
Religious affiliation	▪ Christian: 86% ▪ Other: 14%	-
PMH psychiatric	▪ 0%	-
First-degree relative diagnosed with cancer	▪ None: 43% ▪ One-two: 28% ▪ Three+: 29%	-
Performance status (mean KPS)	80	70-100
Time met diagnosis (months)	10.6	0.5-60
Primary cancer	▪ Lung: 48% ▪ Prostate: 14% ▪ Other: 38%	-
Metastatic tumor sites	▪ Bones: 39% ▪ Brain: 19% ▪ Two sites+: 42%	-
Current treatment site for palliative radiation	▪ Bone: 43% ▪ Brain: 29% ▪ Lung: 19% ▪ Other: 9%	-
Prior treatments for metastasis	▪ None: 38% ▪ Had: 62%	-

The pilot testing phase included twenty-seven (27) patients, seen between November 2016 and February 2017. The mean age was 68.14 years old, with a range from 40 to 92. 62% of patients were male, and 38% female. For the marital status, 14% were single, 52% married, and 34% widowed.

60% of patients were French Canadian, 10% English Canadian, and 30% of another ethnic origin. 19% of patients had no children, and 62% had one or two children. For the education level, 10% had an elementary school level, 57% high school, and 33% had a university level of education. 86% described their religious affiliation as Christian, and 14% as other. None had a past psychiatric history. 45% had no first-degree relative diagnosed with cancer, 28% had one or two, and 29% had three or more.

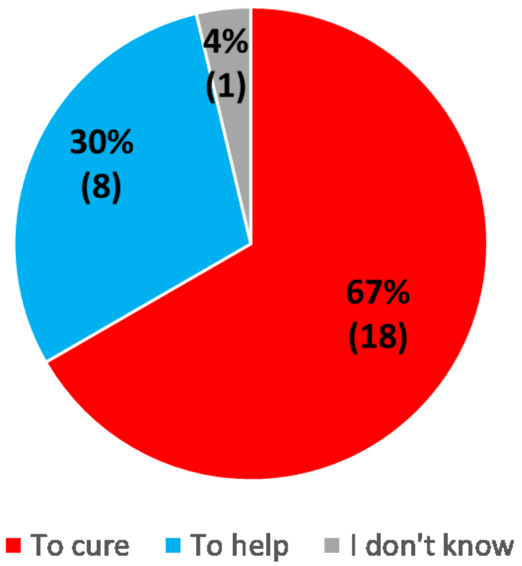
The mean KPS was 80, with a range from 70 to 100. The time since the diagnosis of metastatic disease was 10.6 months, with a range from 2 weeks to 60 months. The most common primary cancer was lung with 48%, prostate for 14%, and the rest for 38%. The most common metastatic tumor site was bones for 39%, brain for 19%, and two sites or more for 42%. The current treatment site for palliative radiation was bones for 43%, brain for 29%, lung for 19%, and another site for 9%. 62% had prior treatments since the diagnosis of metastatic disease.

Figure 5. Information preferences



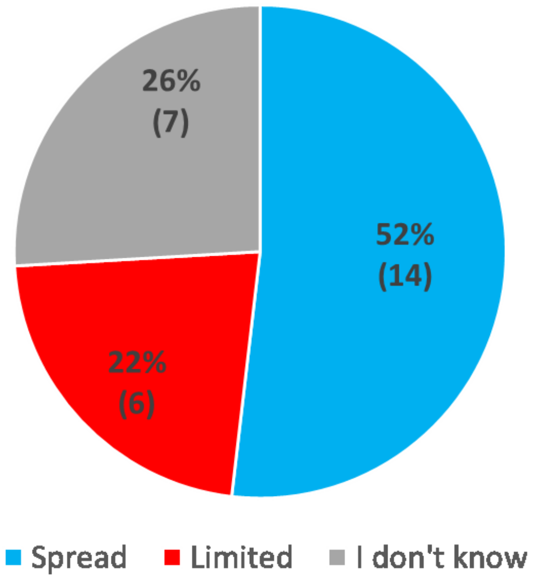
For the part 1 of the questionnaire, the patients answered if they preferred to receive all the information available, some or none. 70% (19 patients) wanted to receive all the information, 26% (7) to have some information, and 4% (1) wanted to have no information.

Figure 6. Information understanding – goal of treatment (question 1)



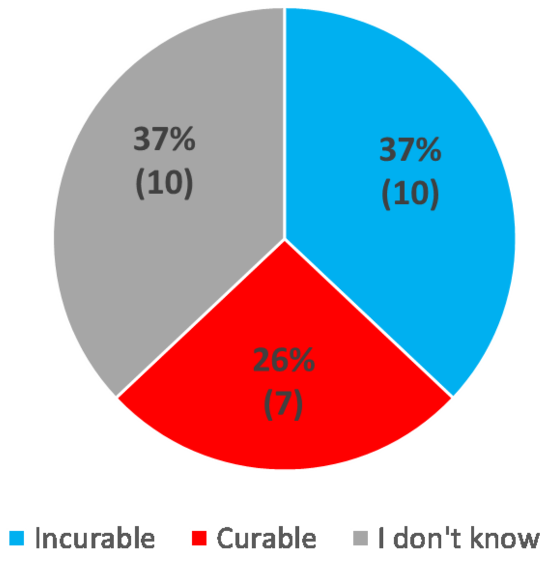
For the part 2 of the questionnaire, four items were provided to assess understanding on the extent and prognosis of the disease – the question 1 assessed the understanding of the goal of treatment in patients diagnosed with metastatic cancer and referred for a treatment to palliate symptoms ("what is the goal of your treatment now?"). For 67% (18 patients), the current goal was to cure their cancer, 30% (8 patients) to help or palliate symptoms, and 4% (1 patient) answered that he or she didn't know.

Figure 7. Information understanding – extent of disease (question 2)



For the question 2, the understanding of extent of disease was assessed ("in which area is your cancer now?") – spread (stage four), limited (to the initial organ) or I don't know. 22% (n = 6) of patients described their cancer as limited to the primary organ or site, 52% described it as spread to other areas of their body, and 26% (7) that they didn't know.

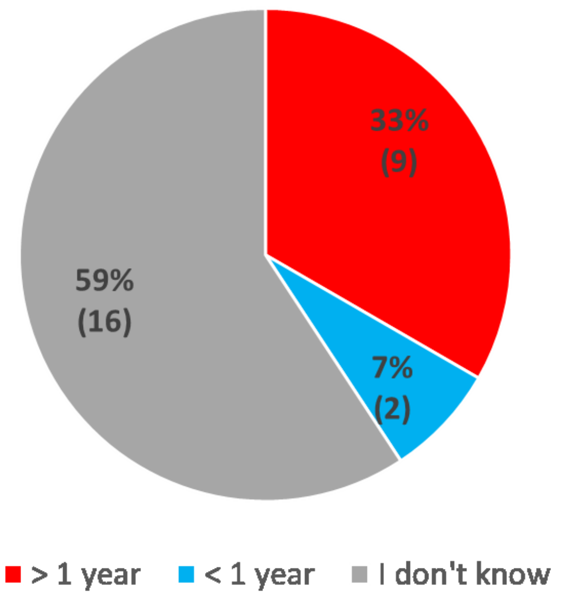
Figure 8. Information understanding – disease status (question 3)



For the question 3, the disease status was assessed ("your cancer now is considered") as: curable, incurable, or don't know. This goal of this question is to evaluate the understanding that metastatic cancer can be treated, but not eradicated – cured.

Most reported considered their cancer curable or did not know, for 26% (n = 7) and 37% (n = 10) respectively. There were 37% (n = 10) that considered it incurable.

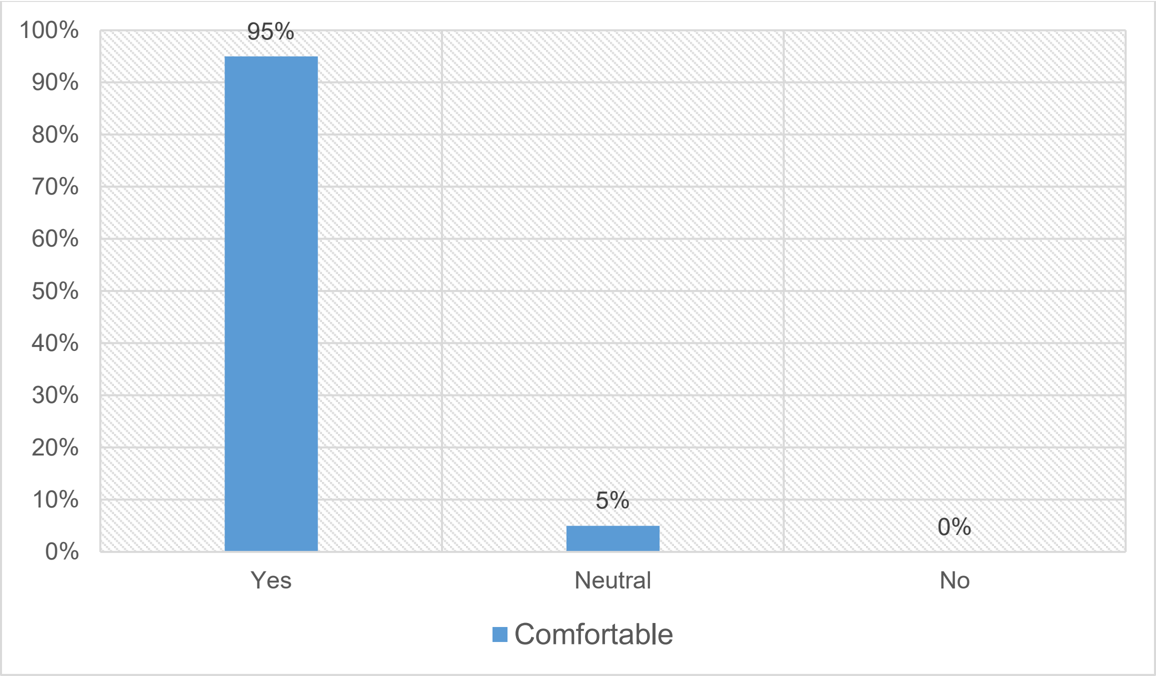
Figure 9. Information understanding – additional survival from treatment (question 4)



For the question 4, the additional survival from treatment was assessed ("for how long, if at all, is the treatment going to prolong your life?"): more than a year added from the current treatment, less than a year, or don't know. The goal of this question was to evaluate the comprehension that treatments for metastatic cancer allow to palliate for symptoms and could add a few months of overall survival, but less than a year in most cases.

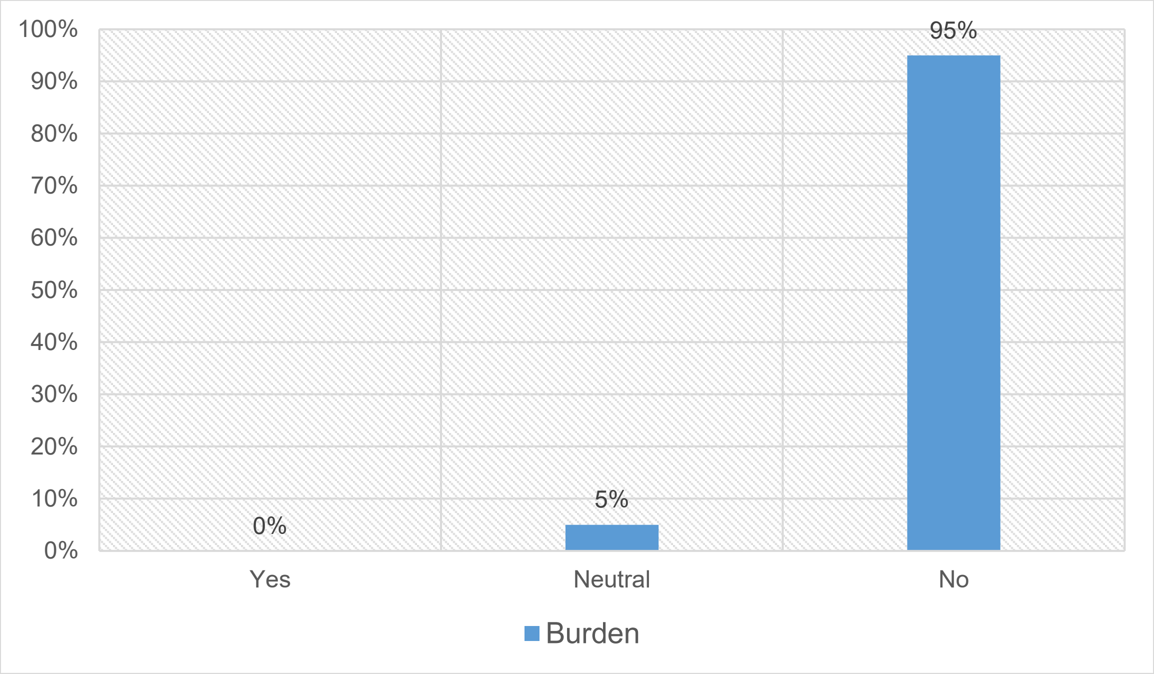
Most mentioned not knowing, 59% (n = 16), and 7% (n = 2) considered that the current palliative treatments could add less than a year of additional survival. There were 33% (n = 9) that considered the current treatment as adding a year or more to their survival.

Figure 10. Patient acceptability - comfortable (question 1)



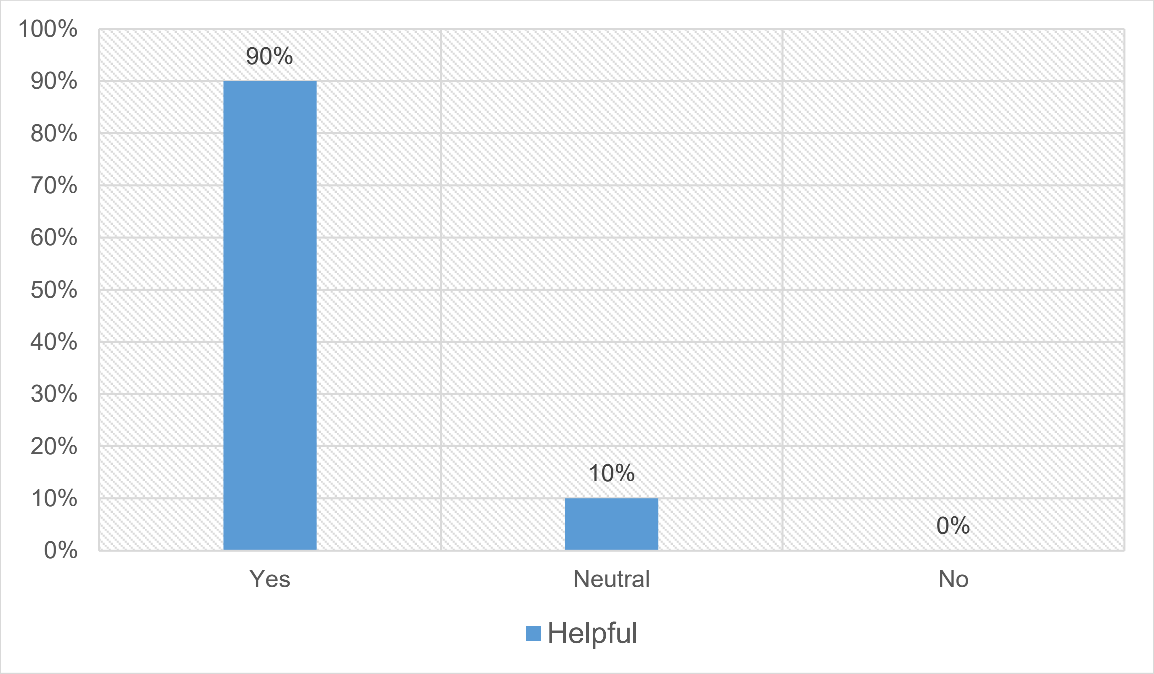
For the first question of the patient acceptability survey, patients were asked if they "were comfortable to answer this questionnaire". 95% of the patients described being comfortable to answer, 5% described being neutral, and none described being uncomfortable answering the questions. Our aim was to create a helpful tool that would empower patients, and not induce harm.

Figure 11. Patient acceptability - burden (question 2)



For the second question of the patient acceptability survey, patients were asked if "completing this questionnaire was a burden". 95% of the patients described the questionnaire as not a burden, 5% described being neutral, and no patient described it as a burden.

Figure 12. Patient acceptability - helpful for information (question 3)



For the third and last question of the patient acceptability survey, patients were asked if "completing the questionnaire was important to help obtaining information about the prognosis of their cancer now". 90% of the patients described the tool as helpful and important to obtain information about their cancer, 10% being neutral, and none as unhelpful.

The first questions of the PAS assessed the absence of harm from the tool, while this question evaluates the added benefit in terms of information gain for patients.

From the perspective of healthcare professionals that used the tool, doctors reported a facilitated and stimulated discussion after the use of the questionnaire. Patients were described as more open to express their concerns and their questions about the extent of disease, their staging, their prognosis, the tests that were done – including imaging and biopsies.

There was no distress reported in patients from doctors after the use of the questionnaire, and corroborated in the Patient acceptability survey. This was a concern reported during the review from healthcare professionals in ensuring that the questionnaire would benefit patients, and "do no harm". From our experience using this tool, we also observed that there was no distress, and the opposite – patients feeling more comfortable discussing their fears, wanting to understand what is the status of their cancer, and expressing their apprehensions and worries.

CHAPTER 4 – Discussion

The findings from this research highlight inaccurate understanding for most patients about the rationale of their medical care. Half of the patients assessed understanding that their cancer has spread to other organs, but the other half beliefs that the cancer is limited to the initial organ or doesn't know the extent of their disease.

The survey constitutes an important component of the acceptability and feasibility of the tool in ensuring that it is safe, and not causing discomfort, distress or a source of frustration for patients. In the context of metastatic cancer, patients often have multiple doctors following them, multiple appointments, and often discomfort or pain or side effects from treatments – thus stressing the importance of ensuring that we don't add an additional "burden" on them. The findings from the survey also highlight the usefulness of such tool in an era of unlimited sources of information through anecdotal experiences, and internet.

CHAPTER 5 Conclusions and Recommendations

This research project included a review of the literature, the creation and pilot testing of a questionnaire to rapidly assess awareness of incurable disease (AID) in patients with metastatic cancer (stage IV). The four-question screening tool was found to be acceptable, quick to complete, not causing distress, and useful to obtain pertinent information for patients and to facilitate the dialogue between patient and doctor about the extent and prognosis of their cancer. This information can help healthcare professionals to have the patients clearly informed and engaged in the decisions of future treatments.

The fact that this cohort included patients with stage IV metastatic cancer and already seen by different healthcare professionals gave us the impression that a high number of patients would be aware of this condition. However, we observed that patients didn't have an accurate understanding of the incurable nature of their metastatic cancer and of the current treatment goal. These findings must be confirmed in a larger cohort of patients and warrant further research to examine the reasons for the inaccurate information.

In summary, the AID questionnaire seems to be a clinically useful tool to help patients and healthcare professionals to be open for discussions on the extent of the disease, the goals of treatments, available options, open studies, and to set realistic goals. It is simple and quick to complete, could be easily implemented in different cancer care settings.

Bibliography

[1] Abazari P, Taleghani F, Hematti S, Ehsani M, "Exploring perceptions and preferences of patients, families, physicians, and nurses regarding cancer disclosure: a descriptive qualitative study," *Support Care Cancer,* no. 11, pp. 4651-9, 2016.

[2] Porensky EK, Carpenter BD, "Breaking bad news: Effects of forecasting diagnosis and framing prognosis," *Patient Educ Couns,* no. 1, pp. 68-76, 2016.

[3] Ptacek JT, Eberhardt TL, "Breaking bad news: A review of the literature," *JAMA,* no. 276, pp. 496-502, 1996.

[4] Ong LML, de Haes JCJM, Hoos AM, et al, "Doctor-patient communication: A review of the literature," *Soc Sci Med,* no. 40, pp. 903-918, 1995.

[5] Ley P, "Communicating with Patients: Improving Communication, Satisfaction and Compliance," *New York: Croom Helm,* 1988.

[6] Baile WF, Buckman R, Lenzi R, et al, "SPIKES—A six-step protocol for delivering bad news: Application to the patient with cancer," *Oncologist,* no. 5, pp. 302-311, 2000.

[7] Clayton J.M., Butow PN., Tattersall RJ., et al., "Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions

about prognosis and end of life care," *Journal of Clinical Oncology,* no. 25(6), pp. 715-723, 2007.

[8] Parker PA, Baile WF, deMoore C, et al, "Breaking bad news about cancer: Patients' preferences for communication," *J Clin Oncol,* no. 19, pp. 2049-2056, 2001.

[9] Christakis NA, Death Foretold, "Prophecy and Prognosis in Medical Care," *University of Chicago Press,* 1999.

[10] Butow PN, Dowsett S, Hagerty RG, et al, "Communicating prognosis to patients with metastatic disease: What do they really want to know?," *Support Care Cancer,* no. 10, pp. 161-168, 2002.

[11] Cegala DJ, Lenzmeier Broz S, "Physician communication skills training: a review of theoretical backgrounds, objectives and skills," *Med Educ,* no. 36, p. 1044–16, 2002.

[12] Week JC, Catalano PJ, Cronin A, et al, "Patients' Expectations about Effects of Chemotherapy for Advanced Cancer," *N Engl J Med,* no. 367, pp. 1616-25, 2012.

[13] Back AL, Anderson WG, Bunch L et al., "Communication about cancer near the end of life," *Cancer,* no. 113 (7 suppl), pp. 1897-1910, 2008.

[14] Shapiro DE, Boggs SR, Melamed BG, Graham-Pole J, "The effect of varied physician affect on recall, anxiety, and perceptions in women at risk for breast cancer: an analogue study," *Health Psychol,* no. 11, p. 61–6, 1992.

[15] Wallace JA, Daugherty CK., "Emotional responses of oncologists when disclosing prognostic information to patients with terminal disease," *J Clin Oncol,* no. 24 (18 suppl), p. 8520, 2006.

[16] Pollak KI, Arnold RM, Jeffreys AS, et al, "Oncologist communication about emotion during visits with patients with advanced cancer," *J Clin Oncol,* no. 25, pp. 5748-5752, 2007.

[17] Gattelari M, Butow PN, Tattersall MHN et al., "Misunderstanding in cancer patients: why shoot the messenger?," *Ann Oncol,* no. 10, pp. 39-46, 1999.

[18] Clayton, JM. Butow, PN., Arnold, RM , Tattersall, M.H.N, "Discussing life expectancy with terminally ill cancer patients and their carers: a qualitative study," *Support Care Cancer,* no. 13, pp. 733-742, 2005.

[19] Mularski RA, Dy S, Shugarman LR et al., "A systematic review of measures of end-of-life and its outcomes," *Health Serv Res,* no. 42(5), pp. 1848-70, 2007.

[20] Chochinov HM, Tataryn DJ, Wilson KG, et al, "Prognostic awareness and the terminally ill," *Psychosomatics,* no. 41, p. 500–504, 2000.

[21] D'Agostino TA, Atkinson TM, Latella LE, Rogers M, Morrissey D, DeRosa AP, Parker PA, "Promoting patient participation in healthcare interactions through communication skills training: A systematic review," *Patient Educ Couns,* no. 17, pp. 30102-7, 2017.

[22] Stevenson FA, Cox K, Britten N, Dundar Y, "A systematic review of the research on communication between patients and health care professionals about medicines: the consequences for concordance," *Health Expect,* no. 7, pp. 235-45, 2004.

[23] Davis FG, Dolecek TA, McCarthy BJ, Villano JL, "Toward determining the lifetime occurrence of metastatic brain tumors estimated from 2007 United States cancer incidence data," *Neuro Oncol,* no. 9, pp. 1171-7, 2012.

[24] D.Z. Ng, W.L. Tan, W.S. Ong, E.M. Gan, A. Jain, E.-H. Tan, D. Tan, "139PD: Lifetime incidence of brain metastases (BM) in EGFR-mutant (M+) lung cancer treated with first-line EGFR TKIs," *Journal of Thoracic Oncology,* vol. 11, no. 4, p. S117, 2016.

[25] Physician Characteristics and Distribution in the U.S., 2010 Edition, 2004 IMV Medical Information Division, 2003 SROA .

[26] Division of Radiation Oncology, MUHC, "Internal Statistics (unpublished data)".

[27] Smith TJ, Swisher K, "Telling the truth about terminal cancer," *JAMA,* no. 279, pp. 1746-8, 1998.

[28] Bultz BD, Johansen C, "Screening for distress, the 6th vital sign: where are we, and where are we going?," *Psycho-Oncology,* no. 20, p. 569–571, 2011.

[29] Grunfeld E, Urquhart R., "Do Available Questionnaires Measure the Communication Factors That Patients and Families Consider Important at End of Life?," *J Clin Oncol,* no. 26, pp. 3874- 78, 2008.

[30] Robinson G, "Effective doctor–patient communication: building bridges and bridging barriers," *Can J Neurol Sci,* no. 29(suppl 2), p. S30–2, 2002.

[31] Howell D, Mayo S, Currie S, et al, "Canadian Association of Psychosocial Oncology (CAPO); Cancer Journey Action Group of the Canadian Partnership Against Cancer (CPAC). Psychosocial health care needs assessment of adult cancer patients: a consensus-based guideline," *Support Care Cancer,* no. 20, p. 3343–3354, 2012.

[32] Legare F, Ratte S, Gravel K, Graham ID, "Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions," *Patient Educ Couns,* no. 73, pp. 526-35, 2008.

[33] Applebaum AJ, Kolva EA, Kulikowski JR, et al., "Conceptualizing prognostic awareness in advanced cancer: a systematic review," *J Health Psychol,* no. 19(9), pp. 1103-19, 2014.

[34] Carlson LE, Waller A, Mitchell AJ, "Screening for distress and unmet needs in patients with cancer: review and recommendations," *J Clin Oncol,* no. 30, p. 1160–1177, 2012.

[35] Jacobsen PB, Donovan KA, Trask PC, et al, "Screening for psychologic distress in ambulatory cancer patients," *Cancer,* no. 103, p. 1494–1502, 2005.

[36] Mitchell AJ,Vahabzadeh A, MagruderK, "Screening for distress and depression in cancer settings: 10 lessons from 40 years of primary-care research," *Psycho-Oncology,* no. 20, p. 572–584, 2011.

[37] Curtis JR et al., "An approach to understanding the interaction of hope and desire for explicit prognostic information among individuals with severe chronic obstructive pulmonary disease or advanced cancer," *J Palliat Med,* no. 11, p. 61020, 2008.

[38] Johnson JA, Coons SJ, Ergo A, Szava-Kovats G., "Valuation of EuroQOL (EQ-5D) health states in an adult US sample," *Pharmacoeconomics,* no. 13(4), pp. 421-33, 1998 .

[39] Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, Filiberti A, Flechtner H, Fleishman SB, de Haes JC, et al., "The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology," *J Natl Cancer Inst,* no. 85(5), pp. 365-76, 1993.

[40] Groh G, Vyhnalek B, Feddersen B, Führer M, Borasio GD, "Effectiveness of a specialized outpatient palliative care service as experienced by patients and caregivers," *J Palliat Med,* no. 16(8), pp. 848-56, 2013.

[41] Cohen R, Leis AM, Kuhl D, Charbonneau C, Ritvo P, Ashbury FD, "QOLLTI-F: measuring family carer quality of life," *Palliat Med,* no. 20(8), pp. 755-67, 2006.

[42] Schur S, Ebert-Vogel A, Amering M, Masel EK, Neubauer M, Schrott A, Sibitz I, Watzke H, Schrank B, "Validation of the "Quality of Life in Life-Threatening Illness--Family Carer Version" (QOLLTI-F) in German-speaking carers of advanced cancer patients," *Support Care Cancer,* no. 22(10), pp. 2783-91, 2014.

[43] Stadelmaier N, Duguey-Cachet O, Saada Y, Quintard B., "The Basic Documentation for Psycho-Oncology (PO-Bado): an innovative tool to combine screening for psychological distress and patient support at cancer diagnosis," *Psycho-Oncology,* no. 23, p. 307–314, 2014.

[44] Herschbach P, Book K, Brandl T, Keller M, Marten-Mittag B., "The Basic Documentation for Psycho-Oncology (PO-Bado): an expert rating scale for the psychosocial experience of cancer patients," *Onkologie,* no. 31, p. 591–596, 2008.

[45] Andrews G, Slade T, "Interpreting scores on the Kessler Psychological Distress Scale (K10)," *Aust N Z J Public Health,* no. 25(6), pp. 494-7, 2001.

[46] Book K, et al., "Distress screening in oncology—evaluation of the Questionnaire on Distress in Cancer Patients—short form (QSC-R10) in a German sample," *Psycho-Oncology,* no. 20, p. 287–293, 2011.

[47] Cella DF, Tulsky DS, Gray G, Sarafian B, Linn E, Bonomi A, Silberman M, Yellen SB, Winicour P, Brannon J, et al, "The Functional Assessment of Cancer Therapy scale: development and validation of the general measure," *J Clin Oncol,* no. 11(3), pp. 570-9, 1993.

[48] Schipper H, Clinch J, McMurray A, Levitt M, "Measuring the quality of life of cancer patients: the Functional Living Index-Cancer: development and validation," *J Clin Oncol,* no. 2(5), pp. 472-83, 1984.

[49] Ganz PA, Haskell CM, Figlin RA, La Soto N, Siau J., "Estimating the quality of life in a clinical trial of patients with metastatic lung cancer using the Karnofsky performance status and the Functional Living Index--Cancer," *Cancer,* no. 61(4), pp. 849-56, 1988.

[50] Cohen SR, Mount BM, Strobel MG, Bui F, "The McGill Quality of Life Questionnaire: a measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability," *Palliat Med,* no. 9(3), pp. 207-19, 1995.

[51] Torrance GW, Furlong W, Feeny D, Boyle M, "Multi-attribute preference functions. Health Utilities Index," *Pharmacoeconomics,* no. 7(6), pp. 503-20, 1995.

[52] Bosch JL, Hop WC, Kirkels WJ, Schröder FH, "The International Prostate Symptom Score in a community-based sample of men between 55 and 74 years of age: prevalence and correlation of symptoms with age, prostate volume, flow rate and residual urine volume," *Br J Urol,* no. 75(5), pp. 622-30, 1995.

[53] NCCN Clinical Practice Guidelines, "NCCN Distress Thermometer," *NCCN Guidelines®,* no. Version 1.2016, 05/06/16.

[54] Wei JT, Dunn RL, Litwin MS, Sandler HM, Sanda MG, "Development and validation of the expanded prostate cancer index composite (EPIC) for comprehensive assessment of health-related quality of life in men with prostate cancer," *Urology,* no. 56(6), pp. 899-905, 2000.

[55] Richardson J, Iezzi A, Khan MA, Maxwell A, "Validity and reliability of the Assessment of Quality of Life (AQoL)-8D multi-attribute utility instrument," *Patient,* no. 7(1), pp. 85-96, 2014.

[56] Jefford M, Mileshkin L, Richards K, et al., "Rapid screening for depression – validation of the Brief Case-Find for Depression (BCD) in medical oncology and palliative care patients," *Br J Cancer,* no. 91, p. 900–906, 2004.

[57] Crook JM, O'Callaghan CJ, Duncan G, Dearnaley DP, Higano CS, Horwitz EM, Frymire E, Malone S, Chin J, Nabid A, Warde P, Corbett T, Angyalfi S, Goldenberg SL, Gospodarowicz MK, Saad F, Logue JP, Hall E, Schellhammer PF, Ding K, Klotz L, "Intermittent androgen suppression for rising PSA level after radiotherapy," *N Engl J Med,* no. 367(10), pp. 895-903, 2012.

[58] Cleeland CS, Ryan KM, "Pain assessment: global use of the Brief Pain Inventory," *Ann Acad Med Singapore,* no. 23(2), pp. 129-38, 1994.

[59] Zigmond AS, Snaith RP., "The Hospital Anxiety and Depression Scale," *Acta Psychiatr Scand,* no. 67, p. 361–370, 1983.

[60] Singer S, Kuhnt S, Götze H, et al., "Hospital anxiety and depression scale cutoff scores for cancer patients in acute care," *Br J Cancer,* no. 100, p. 908–912, 2009.

[61] Lovibond PF, Lovibond SH, "The structure of negative emotional states: comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories," *Behav Res Ther,* no. 33(3), pp. 335-43, 1995.

[62] Ware J Jr, Kosinski M, Keller SD, "A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity," *Med Care,* no. 34(3), pp. 220-33, 1996.

[63] Keller BK, Magnuson TM, Cernin PA, Stoner JA, Potter JF, "The significance of social network in a geriatric assessment population," *Aging Clin Exp Res,* no. 15(6), pp. 512-7, 2003.

[64] Hunt SM, McKenna SP, McEwen J, Backett EM, Williams J, Papp E, "A quantitative approach to perceived health status: a validation study," *J Epidemiol Community Health,* no. 34(4), pp. 281-6, 1980.

[65] Diener E, Emmons RA, Larsen RJ, Griffin S, "The Satisfaction With Life Scale," *J Pers Assess,* no. 49(1), pp. 71-5, 1985.

[66] Ferrans CE, Powers MJ, "Quality of life index: development and psychometric properties," *ANS Adv Nurs Sci,* no. 8(1), pp. 15-24, 1985.

[67] Taylor S, et al., "The Three-item ALERT-B Questionnaire Provides a Validated Screening Tool to Detect Chronic Gastrointestinal Symptoms after Pelvic Radiotherapy in Cancer Survivors," *Clinical Oncology,* 2016.

[68] de Jong et al., "The Quality of Working Life Questionnaire for Cancer Survivors (QWLQ-CS): a Pre-test Study," *BMC Health Services Research,* no. 16, p. 194, 2016.

[69] Baudot et al., "Validation of a questionnaire assessing patients' adherence and skill level of management for oral capecitabine treatment," *Bull Cancer,* no. 103(3, pp. 241-51, 2016 .

[70] Stewart M, Brown JB, Donner A, McWhinney IR, Oates J, Weston WW, Jordan J, "The impact of patient-centered care on outcomes," *J Fam Pract,* no. 49(9), pp. 796-804, 2000.

[71] Hudon C, Fortin M, Haggerty JL, Lambert M, Poitras ME, "Measuring patients' perceptions of patient-centered care: a systematic review of tools for family medicine," *Ann Fam Med,* no. 9(2), pp. 155-64, 2011.

[72] Hibbard JH, Stockard J, Mahoney ER, Tusler M, "Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers," *Health Serv Res,* no. 39(4 Pt 1), pp. 1005-26, 2004.

[73] Bodenheimer T, Lorig K, Holman H, Grumbach K, "Patient self-management of chronic disease in primary care," *JAMA,* no. 288(19), pp. 2469-75, 2002.

[74] Li M, Green E, "The Ontario Psychosocial Oncology Framework: a quality improvement tool," *Psychooncology,* no. 22(5), pp. 1177-9, 2013.

[75] Breitbart W, Rosenfeld B, Pessin H, Kaim M, Funesti-Esch J, Galietta M, Nelson CJ, Brescia R, "Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer," *JAMA,* no. 284(22), pp. 2907-11, 2000.

Appendices

Appendix A: Questionnaires and surveys used in research

Questionnaire: Information about diagnosis and prognosis of cancer disease

MRN: ____________________________________
Date (DD/MM/YYYY): _______________________
Primary: __________________________________

Part I

We believe that wanting to know all, some or none of the information about your disease is particular to each patient. People cope with their illness differently. Some patients like to know all the details about their disease, some prefer limited information, some prefer not to know or to know very little, and some prefer that their family knows on their behalf. What do you prefer?

a) To know all the details   b) To have limited information   c) Not to know

---

Part II (for patients who want to know all or limited information)

Please turn the page.

Part II (for patients who want to know all or limited information)

Please circle the answers that best describe your cancer now.

1. What is the goal (or reason) of the treatment of your cancer now?
  a) To cure or try to cure the cancer
  b) To help with symptoms, but not to cure
  c) I don’t know

2. In which area is your cancer now?
  a) In the organ or region where it started (limited stage)
  b) In other parts of the body (stage four)
  c) I don’t know

3. Your cancer now is considered:
  a) Not curable
  b) Curable
  c) I don’t know

4. For how long, if at all, is your cancer treatment now likely to prolong your life?
  a) Less than a year
  b) More than a year
  c) I don’t know

Questionnaire: Information sur le diagnostic et pronostic de cancer

MRN: ____
Date (DD/MM/YYYY): _________________________
Primaire: _____________________________________

Partie I

Nous pensons que de vouloir savoir toutes, certaines ou aucune des informations à propos de votre maladie est particulier à chaque patient. Les gens font face à leur maladie de manières différentes. Certains patients préfèrent avoir tous les détails sur leur maladie, certains préfèrent avoir une quantité limitée d'information, certains préfèrent ne rien savoir ou avoir très peu d'information, et certains préfèrent que leur famille sache à leur place. Que préférez-vous?

a) Connaitre tous les détails   b) Quantité limitée d'informations   c) Ne rien savoir

---

Partie II (pour les patients qui veulent toutes ou certaines informations)

S'il vous plait tourner la page.

Partie II (pour les patients qui veulent toutes ou certaines informations)

S'il vous plait encerclez la ou les réponses qui décrivent le mieux votre maladie aujourd'hui.

1. Quel est le but (ou la raison) de votre prochain traitement aujourd'hui?

a) Guérir ou essayer de guérir mon cancer
b) Aider avec les symptômes, mais pas guérir
c) Je ne sais pas

2. Dans quelle(s) région(s) se situe votre cancer aujourd'hui?

a) Dans l'organe ou la région où il a commencé (stade limité)
b) Dans d'autres régions du corps (stage quatre)
c) Je ne sais pas

3. Votre cancer, aujourd'hui, est considéré:

a) Pas curable
b) Curable
c) Je ne sais pas

4. Pour combien de temps, voire pas du tout, est-ce que votre prochain traitement est susceptible de prolonger votre vie?

a) Moins qu'une année
b) Plus qu'une année
c) Je ne sais pas

Survey: patient acceptability

MRN: ____________________________________
Date (DD/MM/YYYY): _______________________
Primary: __________________________________

1) Were you comfortable to answer this questionnaire?

a) Yes   b) No   c) Neutral

2) Did you find completing this questionnaire a burden?

a) Yes   b) No   c) Neutral

3) Completing this questionnaire was important to help me obtaining information about the prognosis of my cancer now.

a) Yes   b) No   c) Neutral

Sondage: acceptabilité par le patient

MRN: ____________________________________
Date (DD/MM/YYYY): _______________________
Primaire: __________________________________

1) Étiez-vous confortable à répondre à ce questionnaire?

a) Oui b) Non c) Neutre

2) Avez-vous trouvé le fait de remplir ce questionnaire un fardeau?

a) Oui b) Non c) Neutre

3) Compléter ce questionnaire était important pour m’aider à obtenir de l’information sur le pronostic de mon cancer en ce moment.

a) Oui b) Non c) Neutre