Survey on Current Policies and Practices around Communicating Bad News to Patients and Families in African Oncology Settings

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1. BACKGROUND AND SIGNIFICANCE

<u>Communication in cross-cultural and under-resourced contexts</u>

Open communication is now encouraged for ethical, legal and clinical management purposes, and open communication skills are part of an integrated national cancer plan[1,2]. However, in under-resourced settings where access to cancer treatment is limited and where many cases of cancer present at a late stage, breaking the news of a cancer diagnosis to a patient may be avoided or delayed for a variety of reasons[3,4]. In fact, although telling the truth to cancer patients is seen as imperative in High Income Countries (HICs), the practice of truth telling varies across cultures and can encounter a variety of barriers such as the patients and their proxies' cultural beliefs and practices, local health care professionals and health institutions, and various environmental factors[5,6].

Culture can be defined as a system of beliefs, values and customs that is shared by a group and is used to interpret experiences and behaviors[7]. One's culture can thus play an important role in their health-related values, beliefs and behaviors, and impact how they (and their communities) approach medical professionals and the diagnosis and management of cancer[7]. As a collectivist culture, some African patients may consider approaching their family members, local leaders, and traditional healers for counselling before approaching a medical professional, as this is how they communally value managing health-related issues. This pattern of consultation can cause diagnostic delays and impact adherence to treatment, which can in part explain late stage presentations[8-10]. Furthermore, cancer has been previously labeled as being a Western-based disease in many parts of Africa[11,12]. This stigma arises from specific sociocultural and religious beliefs, which mediate how one values the role of a threat such as the diagnosis of a cancer (e.g., fatalistic perception of the disease, perception of its life-threatening nature), and from common disease-related misconceptions, whereby cancer may be seen as a communicable and contagious disease[12-14]. As such, in some cultures, a cancer diagnosis may stigmatize the individual, leading to their rejection from their immediate family and social groups[15]. In other instances, the patient's family can request that clinicians avoid disclosing the cancer diagnosis, as they fear the negative psychological impact of the revelation on the patient[16].

Conversely, the cultural heritage of clinicians, including their medical culture, can affect how they approach patients[4,17,18]. This underlies the concept of cultural competency in clinical care, whereby clinicians need to be attuned to the patient's culture, as this can contribute to disparities in access to healthcare that are commonly experienced by minority and underprivileged populations[7,18]. Another factor that may explain the advanced stage presentation among Africans include the patient's and their family's educational level, their socioeconomic status, and the socioeconomic repercussions of illness in the context of limited financial support[8-10]. While legislative changes may impact economic (e.g., job security) and medical factors (e.g., access to curative or palliative treatment options), the patient's perception of the disease and acceptance of the treatment options depend on effective healthcare systems, patient-clinician relationships and, on a more foundational level, culturally-competent and patient-centered communication[2,17,19].

<u>Impact of communication on diagnosis and decision-making</u>

As culture shapes health-related values and help-seeking behaviors, the awareness of its influence in clinical care must be integrated into clinical communication[7,18]. Theoretically, effective patient-centered communication relies on two foundational layers: interpersonal and instrumental communication[2,20]. The former refers to the qualitative aspects of patient-clinician

interaction, including respectfulness and/or supportiveness of the clinician, relationship building and patient-centeredness. The latter refers to the bidirectional exchange of information between the patient (and their proxies) and the clinician, where the patient is able to describe their symptoms and concerns and where the clinician explains the diagnosis and treatment options[20]. This framework requires the clinician to be attuned to the patient's cultural background and to accordingly tailor the clinical discourse to optimize the patient-clinician rapport, the trust of patients and their proxies and the patient's engagement in decision-making[12]. The importance of communication in building trust, respect and reciprocity should not be overlooked, as these constructs allow to build and maintain a robust patient-clinician relationship, allowing to transmit information, address misconceptions, provide support, and negotiate treatment decisions[21].

<u>Training on sharing serious news</u>

Communication skills training (CST) in sharing serious news and culturally competent counseling has been studied countlessly; however, they have mainly been developed in the context of multi-ethnic populations in High Income Countries (HICs)[13]. In HICs, CST research has focused on providing a conceptual framework to professionals in oncology (e.g., the Comskil and SPIKES models) and addressing cancer-related racial and ethnic disparities, especially, for example, among the African-American population as they are known to experience the highest cancer death rate and the shortest survival as compared to any other racial or ethnic group in the United States[9,19]. Promoting cancer prevention behaviors, expanding knowledge of risk factors, and improving physician-patient communication have demonstrated significant effect in addressing these disparities by optimizing health-related outcomes such as risk perception, self-efficacy, and one's sense of wellbeing[19]. In terms of physician-patient communication, tailored communication (e.g., identity-based tailoring) has been found to be effective and universal, as it relies on the *cultural variance framework*, which suggests that communication is effective when it is culturally sensitive and matches the patient's ethnic and/or cultural identity affiliation rather than being tailored to the race and/or ethnicity alone[19,22]. Indeed, the concepts of 'cultural sensitivity', 'cultural awareness' and 'cultural competency' are now more than ever integral parts of CST of medical students in HICs[18,23-25]. CST programs have also demonstrated positive effects amongst practicing oncologists, as they provide a frame of reference for engaging and easing the process of sharing serious news, which primes these interventions as tools for optimizing cancer care outcomes[26,27].

Comparatively, there is a considerable paucity within the literature assessing the practices and policies of African clinicians in the area of sharing serious news. This paucity can be attributed to the fact that cancer has long been an underemphasized health problem in Africa, as the focus has often been geared towards communicable diseases and child/maternal mortality[28]. This has important repercussions as a lack of guidelines can impact a standard methodology of care, influencing the patient's understanding of symptoms (e.g., perceptions of disease, disability and suffering), and access to care[18]. There is also a considerable lack in reports of African medical professionals in the communication of a cancer diagnosis. A Southwestern Nigerian survey study assessing experience and perceived competence of health professionals (n=113) found that 22% of respondents had formal training in sharing serious news, and yet still experienced poor support from peers during these instances. They concluded that a large proportion of the sample lacked knowledge in sharing serious news in view of the low level of training and little or no knowledge of well-known protocols for sharing serious news[29]. A lack of training in sharing

serious news appears to be a common theme; however, further investigation is needed to be able to apprehend African-specific practices alongside cultural-specific barriers and facilitators to communication to be able to implement culturally-competent interventions to optimize communication skills[11]. The importance of a culturally sensitive communication framework developed by African professionals for the African population can facilitate the discussion and the patient's involvement in cancer care.

Guidelines for sharing serious news

Guidelines for clinician-patient communication in cancer care arise mostly from HICs and need to be studied in Low and Low-Middle Income Countries prior to being systematically applied. An integrative article has outlined these guidelines by reviewing frameworks from the *Australian National Cancer Control Initiative* and the consensus of the *Clinician-Patient Communications Working Panel of the Program in Evidence-Based Care of Cancer Care Ontario*, which was complemented with a literature review on the topic[21].

These guidelines include the following crucial aspects of communication in healthcare: *General Interaction Skills*, *How to Discuss Prognosis*, *How to Prepare Patients for Medical Procedures*, *How to Discuss Treatment Options*, and *Recommended Approach for Discussion of Disease Progression*. It is important to consider that these guidelines consist of a frame of reference for professionals, and while considered clinically relevant, from an empirical point of view some of the underlying findings are based on low-level evidence, highlighting the need for more robust methodological research designs to test their efficacy and effectiveness in the domain of communication throughout the cancer care trajectory[7,21].

Communication models

A model developed for CST in oncology is the Comskil model, which defines seven important components of a consultation; i.e., Communication Goals, Communication Strategies, Skills, Process Tasks, Cognitive Appraisals, Patient Cues and Patient Barriers[30]. Through these components, CST can effectively organize, define and provide explicit descriptive metrics of communication skills.

As communication practices within the African healthcare context has received little attention, it is important to conduct a thorough analysis of these practices, so as to be able to implement specific goals and strategies that align within the African medical and cultural context. The SPIKES model is a valuable step-wise tool that seeks to facilitate a clinician's aptitude, competence and comfortableness in a variety of sharing serious news situations (e.g., disclosure, recurrence/progression, shift from curative to palliative treatment)[26,31,32]. The SPIKES mnemonic stands for: *Setting* (selecting a private place to demonstrate respect and empathy for the patient and their proxies); *Perception* (the clinician should determine the patient's understanding and perceptions before fully presenting the information); *Information* (the clinician should determine how much and what kind of information would be helpful for the patient and their proxies based on their needs and their reactions); *Knowledge* (consists of the step where the serious news is shared); *Empathy* (the clinician acknowledges the emotions and reactions of the patients and the proxies and responds in an appropriate manner); *Summarize or Strategize* (the clinician explains the information in a laymen manner)[31]. Each step emphasizes specific skills that target different aspects of communication, including the verbal, non-verbal, emotional and environmental aspects of sharing serious news[31,33]. A considerable benefit of the SPIKES model lies within its flexibility and patient-centered approach. However, like most frameworks, the SPIKES was

developed in the United States, and further research needs to investigate the feasibility of using such a step-based approach in the context of cross-cultural communication[34]. This aim gains further importance considering that effective communication strategies have been seen to optimize the patient-physician relationship, improve adherence to treatment regimens, improve the patient's prognosis and survival rate and reduce the potential and extent of symptom clusters and distress, which have an important health-cost benefit[1,35,36].

The current study is the first that ultimately seeks to document current policies and practices in sharing serious news in African tertiary care institutions and uses the SPIKES model as a frame of reference to conceptualize communication-related practices. This initial step is crucial as it will allow a better understanding on which to implement training models on communication that are culturally adapted to the African context.

2. SPECIFIC AIMS

To conduct a pan-African electronic survey on policies and practices around sharing of serious news of oncology providers in diverse African healthcare systems prior to an upcoming professional conference in psycho-oncology. The survey is designed to describe current policies and practices around sharing of serious news in adult and pediatric oncology, as well as identify barriers and facilitators to the sharing of serious news in these settings.

To analyze these survey data and report results for discussion and critique during a facilitated, interactive session on sharing of serious news during the psycho-oncology conference. This discussion will enrich and contextualize the survey data, as well as permit cross-cultural adaptation (as needed) of the SPIKES model for the low-income and low-middle-income setting of Africa.

3. RESEARCH METHODS

3.1 Design

An electronic survey will be distributed by e-mail and/or web-based platform via professional associations on the African Continent. The survey will focus on existing policies and practices around sharing of serious news including disclosure of the cancer diagnosis and prognosis to patients and their families. To foster effective dissemination, respondents will be asked support 'snowball sampling' by nominating African-based oncologists who may also like to participate.

Results of the survey will be presented during a facilitated, interactive session on communication of diagnosis and prognosis (i.e., World Café), which purpose will be to (1) present survey results and (2) initiate focused discussions to better understand the context of disclosure versus non-disclosure of diagnostic and prognostic information in adult and pediatric settings, and (3) consider relevance and applicability of selected, published guidelines such as the SPIKES model for the communication of diagnosis and prognosis in Africa, as well as the need for their cross-cultural adaptation.

Survey questions will be based on previous such survey on the topic conducted during the 1998 ASCO Meeting. Sociodemographic and work-related information will also be collected through the survey. Participants will be presented a participation-coupon at the end of the survey asking

them to write down their contact information if they want to be contacted in the future if we wish to further understand certain aspects of the data or follow-up with them in the future.

3.1 Survey Participants

Recruitment of participants will be conducted by contacting key professional African-based organizations involved in the field of oncology, psycho-oncology and palliative medicine. These organizations include:

1. African Organization for Research & Training in Cancer (AORTIC),

2. International Psycho-Oncology Society (IPOS), and

3. Association for Psycho-Oncology in Africa (APOA).

Letters of support from each of these organizations are provided (see attached).

Inclusion criteria

1. Participants must be licensed medical professionals (physicians, nurses) practicing in an African healthcare facility, in which part or all of their practice is in oncology.

2. Participants must be currently employed and have at least 6 months experience in their current position as a medical professional.

Exclusion criteria

1. Participants who are under 18 years of age.

2. Participants who cannot read in English and speak English.

3.2 Procedures

There will be two recruitment procedures carried out in this study. First, electronic surveys will be sent to members of selected professional associations with a cover letter, signed by the association's President (see Appendix A), as well as an outline of the study (see Appendix D) which will serve as a consent form. The outline will include all of the points typically covered in traditional consent, and completion of the survey will automatically indicate that professionals accept participation. Survey participants will remain confidential; i.e., there will be no way of identifying them. Two reminders of the survey will be sent with a 2-week interval each. Second, the same electronic survey will be sent to registered participants of a two-day conference to be held in Nairobi, Kenya in September 2018, organized by the Association for Psycho-Oncology in Africa.

Survey results will be presented at a World Café included on the program of the two-day conference to be held in Nairobi, Kenya in September 2018, organized by the Association of Psycho-Oncology in Africa. The World Café is designed to discuss the topic at hand as well as gather data that will contextualize the survey results. A preliminary canvas has been created (see Appendix C for World Café canvas of questions), which will evolve in light of the survey results. Participants will be considered as expert stakeholders and extensive note taking will be conducted during the World Café discussion to capture ways to culturally adapt communication guidelines to the African context[37].

Measures

Sociodemographic and work-related information will be collected through the survey such as: provider sex, age, profession, specialty, level of education, country, work in public or private sector, years of work in the profession, years of work in oncology, percentage of time spent in direct contact with oncology patients, work in adult or pediatric oncology setting, training received in communication skills.

Survey questions will be based on the 1998 ASCO Meeting survey (Hilden et al., 2001) and the SPIKES model. Open-ended questions will invite participants to elaborate further on policies and practices in sharing of serious news (see Appendix A for the cover letter and B for the survey).

3.3 Project Consultation

The current project was informed by a diverse network of international researchers and clinicians in psycho-oncology who will serve mainly to advise on procedures, findings, and possible future dissemination and/or follow-on studies. A description of these persons and their role is provided below:

- Dr. Melissa Henry is Co-PI (Department of Oncology, Mc Gill University) of this project. She will advise Dr. Lounsbury on data collection, analyses and reporting, and she will foster manuscript development for this project.

- Dr. Chioma Asuzu at the University of Ibadan will provide on-going support and consultation on the project; Head Office of the Association for Psycho-Oncology in Africa (APOA; see attached letter of support).

- Dr. David Kissane at Monash University will provide consultation on the project, as an expert in cancer communications, Past-Chair, Psychiatry and Behavioral Sciences and Founder of the Communication Skills Lab at Memorial Sloan-Kettering Cancer Center, New York, NY. Dr. Kissane is also an esteemed member of the International Psycho-Oncology Society (IPOS).

- Dr. Scott Nichols is a practicing oncology psychiatrist at the Enloe Medical Center in Chico, California. He is a former Psycho-Oncology Fellow, Dept of Psychiatry and Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, New York, NY. He will provide consultation on the project. He is a member of the International Psycho-Oncology Society (IPOS) and has informed the concept and aims for this project.

- Dr. Philip Odiyo, Faraja Cancer Support Trust, Nairobi, Kenya is a practicing psycho-oncologist and Co-Chair of the three-day professional conference on 'Promoting Effective Treatment of Pain and Distress for Cancer Care in Africa' (19-21 September 2018). Preliminary results of the proposed study will be presented in an interactive forum at this conference. Dr. Oidyo is President of the Kenya Chapter of the Association for Psycho-Oncology in Africa (APOA) and he will provide consultation on the project.

- Dr. Vince Okungu, University of Nairobi, Nairobi, Kenya is Fellow at the African Population & Health Research Centre. He will provide consultation on the project.

- Dr. Patricia Parker is the Current Director of the MSKCC ComSkills Lab. She will provide consultation on the project.

- Dr. Maggie Watson is a Visiting Professor, Department of Clinical, Health and Educational Psychology at University College London and a member the Department of Genetics and

Epidemiology, Institute of Cancer Research, UK. She was previously Head of Psychological Medicine at the Royal Marsden Hospital and led a comprehensive psychological and psychiatric service for oncology patients. She is past President of the International Psycho-oncology Society and current Editor-in-Chief of Psycho-oncology: Journal of Psychological, Social and Behavioral Dimensions of Cancer. She will provide consultation to the project.

4. DATA ANALYSIS

4.1 Sample Size

The pool of professionals will be sufficient to allow for recruitment of a representative pool of 200 to 400 participants.

4.2. Analytic Approach

Descriptive statistical and correlational analyses will be conducted to explore common patterns of communication about cancer diagnosis disclosure. Comparative analyses by professional groups and by characteristics of respondents' practice setting will be conducted.

5. HUMAN SUBJECTS PROCEDURES

Web-based RedCap Survey: All participants will review the cover letter, and their completion of the survey will indicate free and informed assent.

There will be no remuneration of participants in this study.

6. RISKS/BENEFITS TO PARTICIPANTS

6.1 Risks

This study involves minimal physical, psychological, social, or other risks to the provider participants. Professionals may feel uncomfortable when they think about communication with oncology patients in their practices, perhaps even more so during the World Café as guidelines for communication of diagnosis and prognosis will be presented and discussed.

6.2 Data Security and Monitoring

Survey data is protected from unauthorized access, use, or disclosure, both online and offline by ensuring that it is stored on computer servers with limited access in controlled facilities with password protection. All members of the research team are educated about internal security policies and procedures.

Survey data collected for this study in online surveys as well as paper versions of the survey will be stored by Dr. David Lounsbury at Albert-Einstein College of Medicine, New York. Dr. Melissa Henry will have access to the survey data as co-PI.

6.3 Benefits

There is no direct benefit to completing the online survey. However, participation in the Association for Psycho-Oncology in Africa meeting will provide an opportunity for African oncologists to exchange perspectives about communication of the cancer diagnosis and

prognosis based on their own professional experiences. Provider participants may derive a sense of satisfaction by contributing to the World Café forum.

In general, study results may ultimately yield significant benefits to providers and to their health systems in the form of revised, improved policies and practices for communicating cancer diagnosis to patients and family members on the African continent.

7. STUDY TIMELINE

June 2018: Obtain ethics approval for the study and contact professional associations for collaboration in distributing the survey to their members; June 2018: Distribution of the survey through professional organizations and first reminder; July: second reminder sent to professionals; August 2018: Data entry and production of a report, with points to discuss during the World Café. September 2018: Distribution of the survey at the onset of the conference and audio-taping of the World Café; October-December 2018: Data analysis of the quantitative and qualitative data; Jan-June 2019: Writing of article and presentation of results.

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