

# **Culturally competent patient-provider communication with Zulu patients diagnosed with osteosarcoma**

By

Ottilia Brown

Submitted in fulfilment of the academic requirements

for the degree of PhD

in the Department of Internal Medicine

School of Clinical Medicine

College of Health Sciences

University of KwaZulu-Natal

Durban

2016

As the candidate's supervisor I have/have not approved this thesis for submission.

Signed: \_\_\_\_\_ Name: \_\_\_\_\_ Date: \_\_\_\_\_

## **Dedication**

This work is dedicated to the brave men and women who have been diagnosed with osteosarcoma, some of whom have succumbed to this disease. Your courage and resilience have left me in awe. Thank you for sharing your journey with me.

## Declaration

I, Otilia Brown, declare that

- (i) The research reported in this dissertation, except where otherwise indicated, is my original work.
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## Acknowledgements

I would like to sincerely thank the following individuals:

Prof Colleen Aldous for being the catalyst for this PhD journey, for believing in me, and for keeping my eye on the prize at all times;

Dr Len Marais for encouraging me and providing prompt and innovative feedback that greatly improved the readability and accessibility of the work;

Prof Dalena van Rooyen for helping me to give birth to this project, providing instrumental feedback and availing valuable resources that has greatly assisted me;

Dr Wilma ten Ham-Baloyi for assisting with the integrative literature review, reviewing the focus group data, independently coding the patient data, availing herself for discussion about evidence-based practice guideline development, and providing support and encouragement;

Dr Veonna Goliath for conducting the focus groups, independently coding the focus group data, engaging in lengthy theme discussions, reviewing the associated manuscripts, and for supporting me and believing in me;

Ms Madeleine Clare for assisting with the database searches;

Ms Nonduduzo Mbokazi and Ms Thembi Kheswa for conducting the patient interviews;

Sr. Leona Thomas for contacting the patient participants;

Ms Julia Martinelli for transcribing the focus group and patient interviews;

Mr Kegan Topper for reviewing the focus group data;

Prof William Ventres for commenting on some of the manuscripts;

The guideline reviewers for providing valuable feedback on the evidence-based practice guideline;

The healthcare provider and patient participants without whom this study would not have been possible.

## **Co-author contribution statements**

### **Co-authors associated with all the chapters, i.e. Chapters 2 to 7 are as follows:**

Prof Aldous has made a substantial contribution to the conception and design of the work; revising it critically for important intellectual content; final approval of the version to be published; and has agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Prof van Rooyen has made a substantial contribution to the conception and design of the work; revising it critically for important intellectual content; final approval of the version to be published; and has agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Dr Marais has made a substantial contribution to the conception and design of the work; revising it critically for important intellectual content; final approval of the version to be published; and has agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

### **Additional co-author for Chapter 2:**

Dr ten Ham-Baloyi has made substantial contributions to the design of the work; and the analysis and interpretation of data for the work; revising the work critically for important intellectual content; final approval of the version to be published; and has agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

### **Additional co-author for Chapters 3, 4 and 5:**

Dr Goliath has made substantial contributions to the data collection, the analysis and interpretation of data for the work; revising the work critically for important intellectual content; final approval of the version to be published; and has agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

## Abstract

**Background:** Communicating the diagnosis and prognosis of cancer is widely documented as a challenging task. Furthermore, ensuring that patients understand their treatment options is considered good practice; however literature in this regard tends to be limited. Performing these tasks in cross-cultural clinical settings complicates patient-provider communication. This study focused on Zulu patients diagnosed with osteosarcoma and was conducted at a tertiary (training) hospital in the province of KwaZulu-Natal (KZN), South Africa. The primary motivation for undertaking this research stemmed from observations in clinical practice that Zulu cultural beliefs and practices play a significant role in the management of osteosarcoma and hence culturally competent communication was an essential requirement at this site. In addition, patients typically present at the study site with locally advanced or metastatic disease. The late presentation of patients and further delays stemming from patients' preferences to fulfil cultural practices results in treatment limitations and very poor prognosis. Healthcare providers in this setting are therefore expected to simultaneously inform patients of the diagnosis of osteosarcoma, the significant limitations with regard to treatment options, and prognostic considerations in a culturally sensitive manner that engenders cooperation in the patient while allowing them the opportunity to fulfil their cultural obligations.

**Aim and Objectives:** This study aimed to develop an evidence-based practice guideline with recommendations for engaging in culturally competent communication with adult Zulu patients regarding the diagnosis, treatment and prognosis of osteosarcoma. Four objectives were devised in order to meet the aim of the study.

**Objective 1:** Conduct an integrative literature review to gather evidence from previous research.

**Objective 2:** Gather evidence from healthcare providers about the approach taken when they discuss osteosarcoma, its treatment and prognosis with Zulu patients as well as the cultural aspects considered during these discussions.

**Objective 3:** Gather evidence from Zulu patients by exploring their understanding of the osteosarcoma diagnosis, its treatment and prognosis, and their experience of patient-provider communication throughout the illness experience was conducted. Patients' cultural descriptions related to the management of osteosarcoma were also elicited.

**Objective 4:** Develop an evidence-based practice guideline for culturally competent patient-provider communication with osteosarcoma patients based on the evidence collected in Objectives 1, 2 and 3.

**Methods:** *Objective 1:* Whittemore and Knafel's approach to conducting an integrative literature review was used. A number of databases were systematically searched and a manual search was also conducted. Specific inclusion and exclusion criteria were set and documents were critically appraised independently by two reviewers. Thirty-five documents were included following these processes. Data extraction and synthesis followed and were also independently verified.

*Objective 2:* We used an exploratory descriptive contextual study design and conducted focus group interviews with professional nurses, allied health professionals, and orthopaedic physicians. Three focus groups with a total of twenty-three participants were conducted. Focus group interviews were audiotaped and transcribed verbatim. We thematically analysed the interview transcripts using Guba's Model of Trustworthiness to ensure rigour.

*Objective 3:* We used a qualitative case study approach with in-depth interviews that were conducted in isiZulu, audiotaped and transcribed verbatim. The transcripts were translated into English and back translated. Transcripts were then analysed thematically. Data were verified using Guba's model of trustworthiness.

*Objective 4:* The AGREE II (Appraisal of Guidelines, Research and Evaluation) appraisal instrument was used as a guide for developing the evidence-based practice guideline. The AGREE II is a 23 item tool comprising six domains, five of which were considered in developing the guideline.

**Results:** The integrative literature review provided directives on how to deliver culturally competent communication to cancer patients. The review also highlighted the grave need for scientifically rigorous research in the field of culturally competent communication in the management of cancer. Our research with the healthcare providers produced a number of strategies for communicating with Zulu patients about the diagnosis, treatment and prognosis of osteosarcoma. These strategies also addressed cultural considerations and provided detailed information on the cultural factors that have to be taken into account when managing Zulu patients diagnosed with osteosarcoma. Challenges encountered with regard to discussing diagnosis, treatment and prognosis also emerged. In addition to revealing strategies and challenges that are confirmed in the literature, this study also unearthed unique strategies and challenges peculiar to this cross-cultural clinical setting. Despite the uniqueness of some of these strategies, they could be useful in other cross-cultural clinical settings where patients belong to collectivistic cultures, and observe traditions and other practices that are significantly different to Western medical approaches. Our findings also emphasised the importance of training healthcare providers on communication of sensitive information in cross-cultural clinical settings. Our research with Zulu patients diagnosed with osteosarcoma revealed that these patients had extensive understanding of the diagnosis of osteosarcoma, diagnostic procedures, the treatment options applicable to treating osteosarcoma and the side-effects of

chemotherapy. These findings also revealed patients' varied perceptions of and emotional responses to diagnosis and treatment and exposed difference in healthcare provider and patient perceptions of amputation. A significant contribution of the patient study is embedded in Zulu patients' descriptions of their cultural and health beliefs and practices. Specific rituals that are performed to ensure successful outcome of medical procedures, to cleanse patients from bad luck and to address the issue of witchcraft were outlined. Consultation with a reputable traditional healer was flagged as an important cultural practice. However, patients varied in their adherence to traditional belief systems, participation in rituals and the extent to which they deferred decision-making to the family reinforcing the importance of not stereotyping based on pre-existing knowledge of a cultural group. The evidence-based practice guideline was developed based on the findings from the integrative literature review and the studies conducted with the healthcare providers and the Zulu patients. These three sources of evidence facilitated the development of a guideline that presents generic requirements and recommendations for culturally competent communication, and denotes specific strategies for communicating diagnosis, treatment, and prognosis to Zulu patients diagnosed with osteosarcoma. The evidence-based practice guideline also explicates areas that require further research and refinement.

**Conclusions:** The obvious contribution of this research is represented in the evidence-based practice guideline. However, each of the objectives makes a significant contribution to knowledge and practice. This study breaks ground and alerts to the magnitude of research that is required in cross-cultural clinical settings, especially in the South African context as literature in this context with regard to culturally competent communication is very limited. The need for training our healthcare providers in communication of sensitive information in cross-cultural clinical settings strongly emerged from the data. Policy directives that support culturally competent patient-provider communication at a healthcare systems level could significantly contribute to addressing resource constraints and creating clinical environments that are conducive to culturally competent communication.

**Keywords:** cultural competence; communication; cancer; culture; cross-cultural; Zulu; evidence-based practice guideline

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# Chapter 1: Introduction

## 1.1 Chapter Overview

The purpose of this chapter is to provide an overview of the study. The problem statement is outlined and the rationale and purpose of the study are explicated. The study setting and its associated challenges are specified. The aims and objectives of the research are discussed and the structure of the thesis is explained.

## 1.2 Statement of the Problem

Osteosarcoma is the most frequent primary solid malignancy of bone and is derived from primitive mesenchymal cells. Untreated osteosarcomas can result in local and/or metastatic disease progression.<sup>1</sup> Despite advances in treatment of osteosarcoma, survival is dependent on diagnosis prior to progression beyond localised disease.<sup>2</sup> The majority of patients presenting at the study site already have locally advanced or metastatic disease thus negatively affecting treatment options and outcomes for survival.<sup>3</sup> Treatment options include chemotherapy and surgery which can include either limb salvage or amputation.<sup>4</sup> Limb salvage is not always an option in patients with advanced local disease, meaning that amputation, often more as a palliative and quality of life measure is frequently the only surgical option at the study site.

The late presentation of patients at the study site can be partially attributed to misdiagnosis at community health centres or district hospitals.<sup>3</sup> However, observations in clinical practice highlighted the significant role that culture plays in the management of osteosarcoma and also indicated that patients may be in denial about or underestimate the seriousness of their condition. Zulu cultural practices including extensive familial, ancestral and/or traditional healing consultations and rituals before agreeing to certain treatment options may contribute to late presentation of patients and subsequent delays in treatment following diagnosis. It is therefore important for healthcare providers to communicate an understanding of these cultural beliefs while at the same time communicating the urgency of treatment and the negative effect of delay on survival. This requires the skill of communicating with Zulu patients in a culturally sensitive manner that engenders cooperation in the patient while allowing them the opportunity to fulfil their cultural obligations. The purpose of this study was therefore to develop an evidence-based practice guideline for culturally competent patient-provider communication with Zulu patients regarding the diagnosis, treatment, and prognosis of osteosarcoma. Although literature regarding culturally competent communication in international settings is readily available, African literature on the subject is sparse.<sup>5-13</sup> This study breaks ground in that it addresses the problem of culturally competent communication with an identified group of patients in a multicultural South African setting where patient-provider encounters are largely culturally discordant.

### **1.3 Literature Review and Motivation**

The primary motivation for undertaking this research stemmed from observations in clinical practice that Zulu cultural beliefs and practices play a significant role in the management of osteosarcoma and that these beliefs and practices need to be acknowledged when communicating with Zulu patients about the diagnosis, treatment and prognosis of osteosarcoma. In addition, research conducted at this study site<sup>3</sup> indicated that patients diagnosed with osteosarcoma often present for treatment when the disease has already metastasised. According to the literature, patients present late for treatment partly due to misdiagnosis at community health centres (CHCs) or district hospitals.<sup>3</sup> Observations in practice indicated that late presentation could also be partially attributed to Zulu patients' preference to exhaust all traditional healing options before seeking Western medical assistance. A delay in diagnosis and treatment significantly affects prognosis. This study gathered existing evidence from the literature by conducting an integrative literature review, accessed provider practices with regard to their interactions with Zulu patients about osteosarcoma, and gained insight into Zulu patients' accounts of the medical communication process, with the ultimate outcome of an evidence-based practice guideline for culturally competent patient-provider communication. The evidence-based practice guideline that was developed as well as the studies that were conducted in order to develop the guideline had not been done in the South African context before. The issues of patient-provider communication, culture and cancer and associated concepts are now unpacked.

#### **1.3.1 Patient-provider Communication**

Communicating with cancer patients presents the healthcare provider with unique challenges due to the life-threatening nature of the illness. Despite advances in treatment, cancer is still commonly associated with negative emotions such as fear and anxiety.<sup>14</sup> Communicating the diagnosis, treatment and prognosis of cancer with patients is commonly viewed as an unpleasant and complex task.<sup>15</sup> Healthcare providers generally regard communicating about cancer and coping with the emotional responses of patients resulting from such news as stressful.<sup>16</sup> Providers' communication skills have a significant effect on both the patient and the provider. The link between effective patient-provider communication and patient satisfaction, compliance with treatment, quality of life and health outcomes is well-documented.<sup>16-18</sup> Effective patient-provider communication can also positively influence provider burnout, professional satisfaction and decrease litigation.<sup>19</sup> For the cancer patient, effective provider communication can affect the psychological well-being of patients receiving a cancer diagnosis and increase their sense of control and involvement in their care.<sup>20</sup> However this benefit is reciprocal as providers are equally dependent on good patient-provider communication in order to facilitate diagnostic and treatment processes.<sup>18,21</sup>

### 1.3.2 Culture and Patient-provider Communication

Culture can be defined as “a system of beliefs, values, rules and customs that is shared by a group and is used to interpret experiences and direct patterns of behavior”.<sup>22</sup> Culture is an important consideration in clinical care as it plays a significant role in how patients’ health-related values, beliefs and behaviours are shaped.<sup>22</sup> Cultural diversity in South Africa essentially means that patients are more often than not treated by a provider from a different culture to their own. Managing cancer in a multicultural context further complicates the patient-provider relationship.<sup>5</sup> Healthcare providers have to develop an understanding of patient preferences for communication, accommodate the use of nonverbal communication and anticipate the psychosocial impact of terminologies used.<sup>6,7</sup> Understanding all these facets does by no means intimate that providers can adopt a ‘one size fits all’ approach when addressing individuals from certain cultural backgrounds, as various factors such as acculturation and urbanisation may influence individual preferences and communication needs.<sup>7</sup>

Culture affects patients’ and communities’ interaction with cancer, patients’ approaches to its treatment and trust in providers and institutions. Similarly culture has been shown to affect individual professionals’ and institutions’ approach to minority patients.<sup>8</sup> While it is well-known that cultural factors are crucial to diagnosis, treatment and efficient management of illness, overemphasis on culturally categorising patients may result in stereotyping.<sup>9</sup> The other side of this pertains to providers’ awareness of their own cultural backgrounds and contexts<sup>19</sup> and of how this interacts with that of the patient as well as the culture of medicine.<sup>9,10</sup> Disparities in healthcare particularly those related to race and ethnicity, are well-documented and significantly influence access to and optimal use of healthcare services.<sup>11,17,23-25</sup> However, the concept of culture, as earlier defined, is not solely associated with race and ethnicity.<sup>26</sup> It is noteworthy that South Africa presents with disparities in health and wealth that are amongst the highest in the world.<sup>25</sup> Despite post-apartheid South Africa awarding high priority to health equity, a 2008 study by Kon and Lackan showed that Black and Coloured (previously disadvantaged race groups in South Africa) South Africans were still underserved and disadvantaged especially with regard to health care.<sup>27,24</sup> Health disparities have multiple complex causes including genetics, poverty, access to health care, behaviour, and environmental factors.<sup>23</sup> The complex interactions of political and racially motivated policies such as the South African apartheid policies as well as globally documented causes of health disparities such as low socioeconomic status, unemployment, lower levels of education, and occupations and living environments that expose individuals to hazards requiring intervention at many levels.<sup>25,28</sup> While large scale interventions on the policy and institutional level may be required, literature increasingly points to the role that cultural competence can play in reducing health disparities.<sup>8,11,17,29</sup>

### 1.3.3 Cultural Competence and Evidence-based Practice

Cultural competence has varied definitions<sup>30-38</sup> but seems to require the acquisition, integration and application of awareness, knowledge, skills and attitudes regarding cultural differences in order to effectively deliver expert care that meets the unique cultural needs of patients; to manage and reduce cross-cultural misunderstanding in discordant medical encounters; and to successfully negotiate mutual treatment goals with patients and families from different cultural backgrounds. Surbone described cultural competence in medicine as complex and multi-layered.<sup>39</sup> Cultural competence can be achieved via organisational, structural and clinical cultural competence interventions.<sup>29</sup> On the organisational level this refers to ensuring that the leadership and staff compliment of a health care delivery system is diverse and representative of its patient population. Structural cultural competence interventions address structural processes that limit access to quality health care. Clinical cultural competence interventions address provider knowledge of the interaction between sociocultural factors and health beliefs and behaviours as well as equipping providers with the skills to manage these culturally complex interactions. The overall aim of this research is the development of an evidence-based practice guideline for culturally competent patient-provider communication with regard to osteosarcoma diagnosis, treatment and prognosis. This study will address the issue of culturally competent patient-provider communication and therefore falls in the domain of clinical cultural competence interventions. Culturally competent patient-provider communication can be defined as the ability to communicate with awareness and knowledge of how sociocultural factors contribute to healthcare disparities, how cultural factors influence health beliefs and behaviours and in addition possessing the skills to manage these factors effectively in cross-cultural patient-provider contexts.<sup>40</sup>

Inherent in the concept of cultural competence as described above is the patient-centered approach to medicine. This approach, in line with the concept of cultural competence, expects that the provider takes the patient's needs and preferences into account<sup>41</sup> and allows for differences among patients with the same diagnosis and/or from the same ethnic group.<sup>26</sup> Bensing argued that patient-centered medicine and evidence-based medicine are on opposite ends of the continuum as the former purports humanism and a biopsychosocial approach and the latter denotes positivism and a biomedical approach.<sup>41</sup> Both paradigms are deemed relevant and essential, and on close inspection can be practised at the same time despite them housing completely opposite paradigms. Bensing described communication as absolutely key to patient-centered medicine and intimated that strengthening the evidence base of patient-centered medicine lies in conducting communication research.<sup>41</sup> This author firstly calls for research that links communication to health outcomes and also appeals for greater efforts in synthesising the evidence in order to develop evidence-based practice guidelines and protocols. This study is in line with the latter plea with specific emphasis being placed on culturally competent patient-provider communication with Zulu patients diagnosed with osteosarcoma. Although much has been written on the concept of cultural competence, there is a lack of agreement

with regard to how to best implement this at the individual patient care level.<sup>41</sup> The aim is that a review of the evidence from existing literature as well as the generation of new evidence from providers and patients will result in an evidence-based practice guideline for this specific population group. The approach taken in this research therefore reflects the general consensus in the literature that evidence-based practice typically includes three key components namely, research-based evidence available from the literature, clinical expertise and patient preferences.<sup>42,43</sup>

The benefits and purpose of evidence-based practice guidelines are to summarise and synthesise knowledge and innovations in medicine; to reduce variation in practice; and to improve quality of patient care.<sup>44,45</sup> Evidence-based practice guidelines are developed in a transparent and structured manner and reviews, rates and synthesises a large body of evidence resulting in a series of recommendations that can improve provider practice and patient outcomes simultaneously. This study concludes with the developed guidelines being reviewed by an expert panel consisting of people with expertise in clinical content; experts in literature reviews or guideline development, or both; and potential users of the guideline.<sup>46</sup>

#### **1.4 Background and Study Setting**

This study focused on Zulu patients diagnosed with osteosarcoma and was conducted at a tertiary (training) hospital in the province of KwaZulu-Natal (KZN), South Africa. The primary motivation for undertaking this research stemmed from observations in clinical practice that Zulu cultural beliefs and practices play a significant role in the management of osteosarcoma and hence culturally competent communication was an essential requirement at this site. KwaZulu-Natal has a population of 10.9 million people of a total South African population of 54 956 900 million.<sup>47</sup> More than half of the province is rural, unemployment rates are high and literacy has been observed as a challenge in some of the patients presenting at this tertiary facility.<sup>48,49</sup> Regarding poverty levels, 56.6% of the KZN population live below the upper-bound poverty line (R620 per capita per month in 2011 prices).<sup>48</sup> The majority of the KwaZulu-Natal population is classified as Zulu. The Zulu people are indigenous to South Africa and speak isiZulu, one of South Africa's 11 official languages. Zulu patients also typically engage in cultural health beliefs and practices that are in contrast to the Western medical model within which medical training is housed. They may conceptualise illness as resulting from displeasing the ancestors, witchcraft or troublesome social relationships.<sup>50,51</sup> Rituals are often used to communicate with God and the ancestors in order to achieve healing. Zulu patients may also consult traditional healers who are viewed as a medium between the ancestors and God and who treat the patient holistically taking into account the physical, psychological, spiritual and social.<sup>52,53</sup> Depending on the type of traditional healer consulted – sangoma (diviner), inyanga (traditional doctor or herbalist), or umthandazi (faith healer), different healing practices and rituals are performed.<sup>53</sup>

The study site forms part of the national public health system that serves more than 80% of the South African population. The national public health system provides care to patients who do not have sufficient economic resources to access private healthcare.<sup>25,54</sup> The healthcare system in KZN uses a referral system and specific referral patterns are followed. Patients may present at the local clinic or district hospital and may then be referred to a regional or tertiary hospital depending on the nature of the presenting problem. The KZN Department of Health has a transport system which brings patients from the local hospital to the tertiary facility. However, patients still have to transport themselves from home to their local hospital in order to access the hospital transport. Patients may travel as far as 450 kilometres to receive tertiary services. The hospital where the study was conducted is a tertiary referral hospital and provides specialised consultative health services to Western KZN. This facility serves a population of approximately 3.5 million. The Tumour Sepsis and Reconstruction (TSR) Unit, which forms part of the Orthopaedic Surgery Department is dedicated to the treatment of musculoskeletal tumours and due to its specialisation, receives referrals from areas within KZN and outside the province that are not part of the referral system. The unit uses a multidisciplinary team (MDT) approach to managing patients diagnosed with osteosarcoma. The MDT consists of orthopaedic consultants and registrars; nurses from the orthopaedic and oncology outpatient clinics and wards; and allied health professionals including dietitians, occupational therapists, physiotherapists, social workers, and clinical psychologists. Medical encounters are largely culturally discordant at this tertiary hospital. HCPs receive medical training mostly in English or at some universities in Afrikaans and the majority of healthcare professionals are not of Zulu origin.

## **1.5 The Aim and Objectives of the Study**

### **1.5.1 The Aim of the Study**

The overall aim of the study was to develop an evidence-based practice guideline for culturally competent patient-provider communication with Zulu patients with regard to osteosarcoma diagnosis, treatment and prognosis.

### **1.5.2 The Objectives of the Study**

**Objective 1:** This objective focused on obtaining research-based evidence from the literature. An integrative literature review was conducted to gather this evidence. The integrative literature review allows for the inclusion of studies with diverse methodologies.<sup>55</sup> It comprises a number of key stages: problem identification, literature search, data evaluation, data analysis and presentation as outlined in Whittemore and Knafl.<sup>55</sup>

**Objective 2:** This objective accessed clinical expertise pertaining to current practices in this cross-cultural setting. An exploratory descriptive contextual study of the approach taken by healthcare providers when discussing osteosarcoma, its treatment and prognosis with patients as well as the

cultural aspects considered during these discussions was conducted. A focus group interview guide consisting of semi-structured questions was used to elicit information regarding the process and content that multidisciplinary team members follow when discussing osteosarcoma with Zulu patients.

**Objective 3:** This objective focused on obtaining information about patient experiences and preferences. An exploratory descriptive contextual study of patients previously treated for osteosarcoma to explore patient understanding of the osteosarcoma diagnosis, its treatment and prognosis, and patient experience of patient-provider communication throughout the illness experience was conducted. Qualitative in-depth semi-structured interviews were conducted to gather this information. Trained fieldworkers conducted the interviews in Zulu.

**Objective 4:** This objective integrated the evidence collected in Objectives 1, 2 and 3 in order to develop an evidence-based practice guideline for culturally competent patient-provider communication with Zulu patients diagnosed with osteosarcoma. The AGREE II (Appraisal of Guidelines, Research and Evaluation) appraisal instrument was used as a guide for developing the evidence-based practice guideline.<sup>56</sup>

## **1.6 Research Design and Methods**

The research design and methods for each of the objectives is briefly outlined.

### **1.6.1 Objective 1: Conducting the integrative literature review**

Whittemore and Knafel's approach was used to conduct the integrative literature review.<sup>55</sup> This approach comprises the following key stages: problem identification, literature search, data evaluation, data analysis and presentation.

**Problem identification:** The review question was formulated using the PICO guide. The following review question was formulated: How is culturally competent patient-provider communication best delivered to adult Zulu patients diagnosed with osteosarcoma?

**Literature search:** An experienced librarian assisted the primary author with selecting the keywords and databases, and with conducting the search. In the period February to May 2015, various electronic databases and evidence-based practice guideline websites were searched. A manual search was also conducted. Inclusion and exclusion criteria were set for the search. An independent reviewer was used to minimise bias in the selection of studies.<sup>57</sup>

**Data evaluation:** The data was evaluated using a comprehensive and frequently used hierarchy system depicting seven levels of evidence.<sup>58</sup> Critical appraisal tools were used to "carefully and systematically examine the documents in order to judge the trustworthiness, value and relevance in a particular context".<sup>59</sup> An independent reviewer was used to ensure that the critical appraisal tools were accurately applied.<sup>57</sup>

**Data analysis:** The goals of this stage are a thorough and unbiased interpretation of primary sources as well as an innovative synthesis of the evidence.<sup>55</sup> Data relevant to the review question were extracted from the included records. The primary investigator conducted the data extraction and coded and content analysed the extracted data. An independent reviewer verified both processes in order to improve the rigour of the data analysis. Data display matrices were developed to facilitate data comparison and synthesis. The researchers employed an iterative process by repeating the data extraction and synthesis numerous times, in order to ensure the verification of the results.

**Data presentation:** The data is presented in the form of tables and text as is outlined in Chapter 2.

#### 1.6.2 Objective 2: Focus groups with health professionals

**Research design and method:** A qualitative exploratory descriptive study design using semi-structured focus group interviews were used to gather data. The interview schedule was piloted to ensure that a broad range of data was being elicited for the purposes of the study. Three focus groups comprising three distinctive groups; orthopaedic consultants and registrars, nurses and allied health professionals, were conducted.

**Participants and sampling:** Census sampling was used as all members of the MDT were approached for participation in the study. Five health professionals could not participate due to scheduling difficulties. The three focus groups comprised a total of twenty-three health professionals.

**Data collection:** An expert in focus group interviewing and qualitative research conducted the interviews. She had no prior contact with the participants. Focus groups were arranged at the hospital as participants work in a high pressured, resource-constrained environment and had to be on hand in the case of emergencies arising.

**Data analysis:** The data were analysed using thematic analysis which is a data analysis technique commonly employed in qualitative research for identifying, analysing, and reporting patterns within data.<sup>60</sup> There are a number of steps in thematic analysis:

- 1 The first step involves familiarising yourself with your data. This entails transcribing data (if necessary), reading and rereading the data, and noting down initial ideas.
- 2 The researcher then generates initial codes. This requires the researcher to code interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
- 3 The researcher then searches for themes by collating codes into potential themes, gathering all data relevant to each potential theme.
- 4 Themes are then reviewed and refined by checking the collated extracts for each theme and observing whether they form a coherent pattern (Level 1). Extracts that do not fit into a theme could be an indication that the theme is problematic and needs to be reworked or could mean that a new theme(s) has to be created for those extracts or alternatively that extracts have to be discarded. A thematic map is now generated of the themes and the researcher can move to Level 2

of this step which involves considering the validity of individual themes in relation to the entire data set.

- 5 Themes are then defined and named. This entails ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells thereby generating clear definitions and names for each theme.
- 6 The researcher then selects vivid, compelling extract examples, relating these back to the research question and literature and presenting a discussion of the findings.<sup>60</sup>

**Trustworthiness:** Guba's model of trustworthiness with its four criteria was utilized to ensure rigour in the qualitative research process.<sup>61</sup> With regard to the criterion of credibility, research methods that are well-established in the qualitative genre were used. The researchers were suitably qualified and had the relevant experience required for the research project. Data verification entailed the processes of independent coding by the focus group interviewer; two rounds of peer review of the themes by two independent qualitative researchers; and a final theme discussion by the principal investigator and the focus group interviewer. Contextual credibility was addressed in that the principal investigator has in-depth knowledge of the participating organisation and ensured that the focus group interviewer had a good understanding of the approach taken in the management of osteosarcoma patients at the study site. The focus group interviewer employed iterative questioning and probing to elicit rich data and verify information. Guba's transferability and dependability was addressed by providing a detailed description of the research context and research procedures followed so that readers are able to decide on the transferability of the findings for their context and to facilitate the future repetition of the research. Dependability was further addressed by providing an operational description of the research design and methods. The confirmability criterion relates to ensuring that the findings reflected the experiences and opinions of the participants and not those of the researcher.<sup>62</sup> The principal investigator works at the study site, hence an experienced independent researcher whom has had no prior contact with the participants conducted the focus groups. The process of bracketing<sup>63</sup> was used while analysing the data and the themes were verified by independent qualitative researchers.

### 1.6.3 Objective 3: In-depth interviews with Zulu patients

**Research design and method:** A qualitative descriptive case study design was used. Semi-structured in-depth interviews were conducted by a Zulu-speaking fieldworker. The interview schedule was piloted to ensure that the appropriate data would be elicited for the purposes of the study.

**Participants and sampling:** Convenience sampling was used to obtain participants for the study.

**Data collection:** Zulu patients were contacted telephonically by Zulu-speaking fieldworkers and invited to participate in the study. Those that agreed to participate travelled to the hospital for the interviews. Where patients already had hospital appointments booked, interviews were scheduled for their convenience on the same day. Patients that were amenable to travelling received a travel allowance.

**Data analysis and trustworthiness:** The data were analysed using thematic analysis.<sup>60</sup> A qualitative research expert independently coded the data following which a data discussion was held to finalise the themes. The research methods are discussed in detail in Chapter 6 and allows for replicability of the study. Guba's model of trustworthiness was used to ensure rigour.<sup>61,62</sup>

#### 1.6.4 Objective 4: Developing the evidence-based practice guideline

The AGREE II (Appraisal of Guidelines, Research and Evaluation) appraisal instrument was used as a guide for developing the evidence-based practice guideline.<sup>64</sup> The purpose of the AGREE II Instrument is to provide a framework for assessing the quality of guidelines; provide a methodological strategy for the development of guidelines; and inform what information should be reported in guidelines and in what manner.<sup>56</sup> The AGREE II is a 23 item tool comprising six domains, five of which were used for developing the guideline. The domain, applicability which refers to the likely barriers and facilitators to implementation, strategies to improve uptake, and resource implications of applying the guideline was beyond the scope of this study. Implementation of the guideline will require training of healthcare providers.

**Domain 1: Scope and Purpose:** This domain is concerned with the overall aim of the guideline, the review question, and the target population.

*Aim of the guideline:* Present healthcare providers treating Zulu patients diagnosed with osteosarcoma with evidence-based recommendations that can facilitate culturally competent communication regarding the diagnosis, treatment and prognosis of osteosarcoma.

*The review question:* How is culturally competent patient-provider communication best delivered to adult Zulu patients diagnosed with osteosarcoma?

*Target group:* Adult Zulu patients diagnosed with osteosarcoma.

**Domain 2: Stakeholder Involvement:** This domain focuses on the extent to which the guideline was developed by the appropriate stakeholders and represents the views of its intended users. The guideline was developed by one of the members of the multidisciplinary team working with Zulu patients diagnosed with osteosarcoma. Healthcare providers working in a multidisciplinary team context with Zulu patients diagnosed with osteosarcoma participated in focus groups. Zulu patients' views and preferences were investigated using in-depth interviews.

**Domain 3: Rigour of Development:** This domain relates to the process used to gather and synthesize the evidence, the methods to formulate the recommendations, and to update them.

*Gathering and synthesising the evidence:* An integrative literature review was conducted to review the existing evidence. Focus groups with healthcare providers and in-depth individual interviews with Zulu patients were conducted in order to contextualise the guideline.

*Formulating the recommendations:* The recommendations were formulated following careful review of the results of the integrative literature review, the focus group interviews and the patient interviews. Duplicate recommendations across these three sources were grouped together. Generic

recommendations were grouped together and recommendations specific for the communication of the diagnosis, treatment and prognosis of osteosarcoma with Zulu patients were presented separately. The guideline was reviewed by an expert panel. The guideline development process was supervised by experienced researchers and clinicians.

**Domain 4: Clarity of Presentation:** This domain deals with the language, structure, and format of the guideline. Care was taken to develop clear and unambiguous recommendations. Headings and subheadings clearly demarcate the different sections of the guideline.

**Domain 5: Editorial Independence:** This domain is concerned with the formulation of recommendations not being unduly biased with competing interests. There are no competing interests to report.

## **1.7 Ethical Considerations**

A number of ethical considerations were important for the purposes of this study.

### **1.7.1 Informed consent**

Informed consent was ensured in this study in that each participant received an information sheet (see Appendix C and D) explaining the nature and purpose of the study, who the researcher is, the issues of confidentiality and anonymity and a contact number should any questions arise. The researcher/fieldworkers collecting the data provided a detailed explanation of the research, its duration and the issues of confidentiality and anonymity. The information sheet also contained the contact details for BREC should the participants be concerned that ethical violations occurred during the research. The information sheet for patients was translated into Zulu.

### **1.7.2 Coercion**

Participants were informed of their right to voluntary consent and their right to withdraw from the study at any time. Patient participants were also reassured that their decision regarding participation in the study did not affect their access to healthcare in any way.

### **1.7.3 Privacy and confidentiality**

An independent qualitative expert that had no prior knowledge of the participants conducted the focus groups. Fieldworkers contacted the Zulu patients and invited them to participate in the study. Although the researcher has knowledge of the identities of the participants gleaned from the consent forms that were completed, these are securely stored and anonymity and confidentiality in reporting of the findings was maintained at all times. Furthermore, transcriptions of the tape recorded focus groups were conducted by an independent transcriber with no prior knowledge of the participants. Anonymity was further ensured through de-identification using codes.

### **1.7.4 Risk of Harm to Patients**

Zulu patients diagnosed with osteosarcoma were approached for participation in the study. Patients were asked about their illness as well as their experience of the healthcare system. There was a concern that retelling their stories could evoke negative emotional responses. Counselling was made available in the event that a participant may have required this. However, osteosarcoma patients are referred to the Clinical Psychology Department before final diagnoses are made. These patients therefore receive ongoing psychological intervention from the time of diagnostic work-up and throughout the treatment process should they agree to this service. In addition, many of these patients receive services from the Social Work Department as well. The risk of harm noted was therefore minimal but was taken into account nonetheless. None of the participants requested counselling following participation in the study.

#### 1.7.5 Ethics Approval

Ethics approval to conduct the study was obtained from the UKZN Bioethics Research and Ethics Committee (BREC) and permission to conduct the study at the institution was obtained from the CEO of Grey's Hospital as well as KZN Health Research and Knowledge Management (Appendix G).

### **1.8 Structure of the Thesis**

The thesis is divided into four parts which are directly linked to the four objectives of the study. Parts one, two and three culminate in Part 4. As stated, evidence-based practice should comprise evidence from 1) research, 2) clinical expertise, and 3) patient preferences.<sup>42,43</sup> Parts one, two and three speak to these three components.

Part 1 comprises the integrative literature review and consists of Chapter 2 entitled: Culturally competent communication in the management of cancer: An integrative literature review.

Part 2 covers the second objective and relates to the focus groups conducted with the healthcare providers. This section comprises three chapters. Chapter 3 entitled: Strategies and challenges for communicating the diagnosis of cancer in cross-cultural clinical settings—Perspectives from South African healthcare professionals, covers the topic of discussing the diagnosis of osteosarcoma with Zulu patients. Chapter 4 entitled: Communicating about treatment of osteosarcoma in cross-cultural clinical settings: A qualitative review of content, process, challenges, and strategies, details the treatment discussion as well as the cultural considerations in this regard. Chapter 5 entitled: Communicating about prognosis with regard to osteosarcoma in a South African cross-cultural clinical setting: strategies and challenges, highlights the prognostic discussion with Zulu patients from the healthcare providers' perspectives.

Part 3 relates to the third objective and comprises Chapter 6 entitled: Communication across the osteosarcoma disease trajectory: Patients' factual, emotional and cultural accounts. This chapter

explores how the diagnosis, treatment and prognostic aspects of osteosarcoma is communicated to patients, their understanding of the diagnosis and treatment of osteosarcoma as well as their experience of the communication of these components. Participants' descriptions of the role of culture in the management of this life-threatening illness are also reported on.

Part 4 outlines the evidence-based practice guideline that was developed based on the data discussed in Parts 1, 2 and 3. Part 4 contains Chapter 7 and is entitled: Culturally competent patient-provider communication with Zulu patients diagnosed with osteosarcoma: An evidence-based practice guideline.

Part 5 outlines the synthesis and discussion of the study. Chapter 8 provides a summary of the main findings and highlights the original contribution of the work. Strengths and weaknesses of the study are discussed; practice implications as well as directions for future research find their home in this section.

### **1.9 Chapter Conclusion**

This chapter outlines the significance of the problem to be studied and provides a substantive background and motivation for the study. The research design and methods is outlined in order to orientate the reader to the methods used to achieve the aim of an evidence-based practice guideline. Patients typically present late for treatment at the study site and the majority of the patients treated at this tertiary facility are Zulu. The poor prognostic outcomes resulting from late presentation and possible further delays as a result of cultural practices poses a number of challenges to healthcare providers with regard to communicating with Zulu patients. Cultural competence therefore has a significant role to play in mediating these challenges and ensuring that health outcomes are maximised. The evidence-based practice guideline therefore offers recommendations for navigating the cross-cultural clinical terrain within which these patients are treated.

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## **Part 1: Conducting the Integrative Literature Review**

There is general consensus in the literature that evidence-based practice generally includes three key components, namely research-based evidence available from the literature, clinical expertise and patient preferences.<sup>1,2</sup> The first part of this study entailed conducting an integrative literature review detailing the existing evidence for culturally competent patient-provider communication in the management of cancer. Specific literature on osteosarcoma was not available hence the decision to focus on cancer while conducting the integrative literature review. Chapter two provides a detailed account of the methods used to conduct the integrative literature review. The review highlighted the grave need for scientifically rigorous research in the field of culturally competent communication with cancer patients. However, the results provide clear directives on how culturally competent patient-provider communication can be delivered to adult patients diagnosed with cancer.

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## **Chapter 2: Culturally competent communication in the management of cancer: An integrative literature review**

Brown O., ten Ham-Baloyi W., Aldous C., Van Rooyen D., Marais LC.

**Published in Global Health Action**

## REVIEW ARTICLE

## Culturally competent patient–provider communication in the management of cancer: An integrative literature review

Ottilia Brown<sup>1\*</sup>, Wilma ten Ham-Baloyi<sup>2</sup>, Dalena (RM) van Rooyen<sup>3</sup>, Colleen Aldous<sup>1</sup> and Leonard Charles Marais<sup>1</sup>

<sup>1</sup>School of Clinical Medicine, University of KwaZulu-Natal, Durban, South Africa; <sup>2</sup>Department of Nursing Science, Nelson Mandela Metropolitan University, Port Elizabeth, South Africa; <sup>3</sup>Faculty of Health Sciences, Nelson Mandela Metropolitan University, Port Elizabeth, South Africa

**Background:** Managing cancer in a multicultural environment poses several challenges, which include the communication between the patient and the healthcare provider. Culture is an important consideration in clinical care as it contributes to shaping patients' health-related values, beliefs, and behaviours. This integrative literature review gathered evidence on how culturally competent patient–provider communication should be delivered to patients diagnosed with cancer.

**Design:** Whittemore and Knaff's approach to conducting an integrative literature review was used. A number of databases were systematically searched and a manual search was also conducted. Specific inclusion and exclusion criteria were set and documents were critically appraised independently by two reviewers. Thirty-five documents were included following these processes. Data extraction and synthesis followed and were also independently verified.

**Results:** Various strategies and personal characteristics and attitudes for culturally competent communication were identified. The importance of culturally competent healthcare systems and models for culturally competent communication were also emphasised. The findings related to all themes should be treated with caution as the results are based mostly on low-level evidence (Level VII).

**Conclusions:** More rigorous research yielding higher levels of evidence is needed in the field of culturally competent patient–provider communication in the management of cancer. Most of the available literature was classified as non-research evidence. The themes that emerged do, however, provide some insight into how culturally competent patient–provider communication may be delivered in order to improve treatment outcomes in patients diagnosed with cancer.

**Keywords:** *cultural competence; patient–provider communication; cancer; oncology; culture*

\*Correspondence to: Ottilia Brown, Grey's Hospital, Clinical Psychology Department, 201 Town Bush Road, Northern Park, Pietermaritzburg, South Africa 3201, Email: ottiliabrown1978@gmail.com

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Received: 20 August 2016; Revised: 11 October 2016; Accepted: 2 November 2016; Published: 30 November 2016

### Introduction

Communicating with cancer patients can be challenging for healthcare providers. The life-threatening nature of the illness, the physical and psychological suffering of cancer patients (1), and the responsibility of conveying complex health information to the patient while also managing their emotions (2) are just some of the challenges impacting patient–provider communication in the cancer setting. Managing cancer in a multicultural context further complicates patient–provider communication (3). Culture can be defined as 'a system of beliefs, values, rules and customs that is shared by a group and is used to interpret ex-

periences and direct patterns of behavior' (4). Culture plays a significant role in how patients' health-related values, beliefs, and behaviours are shaped (4) and affects how patients and communities approach the diagnosis and treatment of cancer as well as their trust towards healthcare providers and institutions (5). Similarly, culture has been shown to affect professionals' and institutions' approach to minority patients (5) and contributes substantially to the existing disparities in access to healthcare for minority and underprivileged patients (1). An example is South Africa as this country presents with disparities in health and wealth that are amongst the

highest in the world (6). The majority of the South African population is classified as African (80.5%) (7) and consists of a number of ethnic groups each with their own African language. South Africa has 11 official languages comprising various African languages, English, and Afrikaans. African patients understand health and illness within a framework of indigenous beliefs which takes the biological, social, emotional and spiritual aspects into account and where cancer may be conceptualised as resulting from witchcraft or conflicts in relationships. Consultation with traditional healers is thus often preferred to Western medicine (8). Late presentation of cancer patients due to a preference for traditional approaches to healing has been reported in local and international studies (8–10). In addition, consultation with family members and the elders is a common practice before any major life decisions (8), including treatment decisions like surgery, are made. South African patients presenting for treatment in the public health sector tend to be confronted with cultural and language discordant medical encounters as healthcare providers are often not of the same cultural background as the patient; may have more urban, Western perspectives of health and illness; and are trained in English or Afrikaans. Similar reflections regarding culturally discordant medical encounters are noted in international literature where countries such as the United States and the United Kingdom serve populations from diverse cultural backgrounds (11–13).

Cultural competence has been proposed as a strategy to improve access to healthcare and the quality of healthcare, and to reduce and/or eliminate health disparities (14–20). Cultural competence has varied definitions (1, 17, 21–27) but seems to require the acquisition, integration, and application of awareness, knowledge, skills, and attitudes regarding cultural differences in order to effectively deliver expert care that meets the unique cultural needs of patients; to manage and reduce cross-cultural misunderstanding in discordant medical encounters; and to successfully negotiate mutual treatment goals with patients and families from different cultural backgrounds. Surbone (1) suggested that culturally competent cancer care can improve treatment outcomes and viewed cultural competence as a requirement for healthcare professionals working in the cancer setting.

Reviewing the literature revealed that there were no systematic or integrative reviews available on culturally competent patient–provider communication with cancer patients. This integrative literature review is part of a broader study for developing an evidence-based practice guideline for culturally competent patient–provider communication with patients diagnosed with osteosarcoma in a specific South African context. Healthcare providers in cross-cultural clinical settings have to be able to communicate an understanding of patients’ cultural beliefs while at the same time communicating the urgency

of intervening and the effect on survival if patients choose to delay intervention while engaging in cultural practices. This integrative literature review aims to provide some insight into how to deliver culturally competent patient–provider communication to adult patients diagnosed with cancer.

## Methods

An integrative literature review was performed in accordance with the guidelines provided by Whittemore and Knafl (28). These authors propose the following key stages: problem identification, literature search, data evaluation, data analysis, and data presentation. This literature review methodology was selected as it allows for the inclusion of studies with diverse methodologies, and for the combination of data from theoretical and empirical literature, to facilitate a more comprehensive understanding of a particular issue or healthcare problem (28). The review question was formulated using the PICO guide (29). The aim of the integrative review was to determine how culturally competent patient–provider communication is best delivered to adult patients diagnosed with cancer.

### Literature search

An experienced librarian assisted the primary author with selecting the keywords and databases, and with conducting the search. In the period February to May 2015, various electronic databases as is depicted in Fig. 1, were searched. Evidence-based practice guideline websites were also searched, including the National Guideline Clearinghouse, National Health and Medical Research Council (NHMRC), New Zealand Guidelines Group (NZGG), Registered Nurses’ Association of Ontario (RNAO), The National Institute for Health and Care Excellence (NICE), Scottish Intercollegiate Guidelines Network (SIGN), eGuidelines, Guidelines International Network, Turning Research into Practice (Trip) Database, Canadian Medical Association (CMA) Infobase, and Joanna Briggs Institute (JBI) Evidence-based Practice Database. A manual search was conducted using Google Scholar and the following websites: ([www.culturediversity.org/cultcomp.htm](http://www.culturediversity.org/cultcomp.htm), [www.diversityrx.org/HTML/DIVRX.htm](http://www.diversityrx.org/HTML/DIVRX.htm), [www.omhrc.gov/templates/](http://www.omhrc.gov/templates/), [www.sis.nlm.nih.gov/outreach/multicultural.html](http://www.sis.nlm.nih.gov/outreach/multicultural.html), [www.npin.cdc.gov/pages/cultural-competence](http://www.npin.cdc.gov/pages/cultural-competence), [www.adventisthealthcare.com/health/equity-and-wellness/](http://www.adventisthealthcare.com/health/equity-and-wellness/), [www.hrsa.gov/culturalcompetence/qualityhealthservices](http://www.hrsa.gov/culturalcompetence/qualityhealthservices), [www.cancer.gov/aboutnci/organization/crchd.iccnetwork.org/pocketguide/](http://www.cancer.gov/aboutnci/organization/crchd.iccnetwork.org/pocketguide/), [www.cdc.gov/cancer/healthdisparities/statistics/ethnic.htm](http://www.cdc.gov/cancer/healthdisparities/statistics/ethnic.htm)).

The following keywords were used in various combinations to conduct the literature searches: patient–provider communication; doctor–patient communication; physician–patient communication; cancer; oncology; cultural competence; culturally competent communication; cross-cultural communication; multicultural communication;

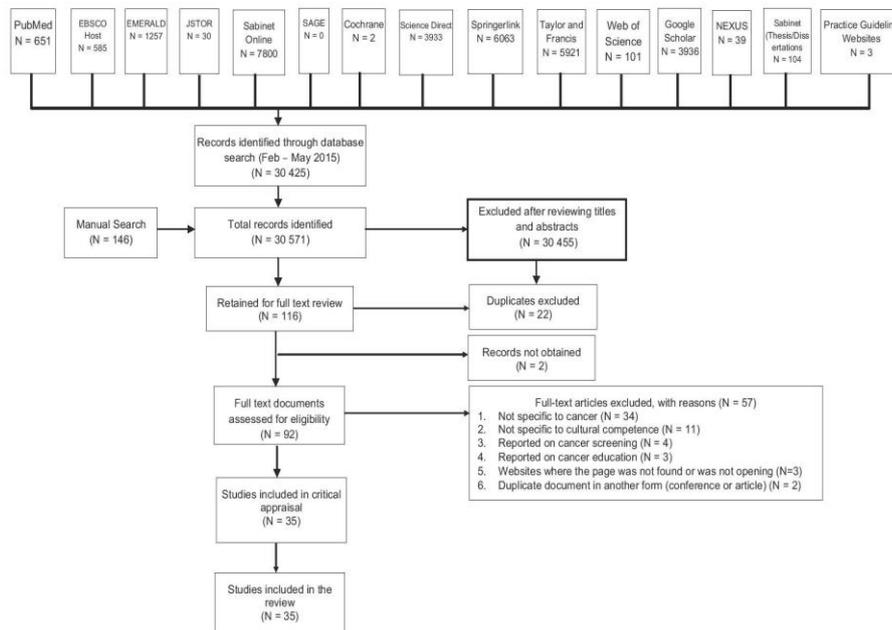


Fig. 1. PRISMA flowchart detailing flow of studies through the review.

and transcultural communication. Various sets of keywords were used that were deemed suitable for the databases, to ensure that no relevant literature was missed.

**Inclusion and exclusion of records**

The following inclusion criteria were used: relevant literature from 1982 was included, as the term ‘cultural competence’ first appeared in the literature in 1982 (30). The literature on cultural competence had to pertain specifically to cancer or to cultural aspects of communication in the context of cancer care, and had to be available in English. Owing to the paucity of research documents available on the topic, non-research documents were also included when these were appraised as relevant to the review question (31).

Regarding exclusion of records, literature that pertained to cultural competence in disciplines other than the context of cancer care was excluded from the review. Literature pertaining to paediatric oncology, cancer

patient education not related to the interaction between patients and healthcare providers, and cancer screening were also excluded. Inclusion and exclusion of records was independently verified by the second author using the inclusion and exclusion criteria. Figure 1 represents the search process for this integrative literature review.

**Data evaluation**

A comprehensive and frequently used hierarchy system (Table 1) was chosen to rate the evidence (32).

Critical appraisal tools were used to carefully and systematically examine the records in order to judge its trustworthiness, and its value and relevance in a particular context (33). The primary author and other authors independently appraised the documents.

Two quantitative studies were appraised using the Health Care Practice Research and Development Unit (HCPREDU) Evaluation Tool for Quantitative Studies (34). Four qualitative studies were appraised using the

Table 1. Rating system for the hierarchy of evidence for intervention/treatment questions (32)

Level I (strongest evidence)	Evidence from a systematic review or meta-analysis of all relevant randomized controlled trials (RCTs) Evidence from evidence-based clinical practice guidelines based on systematic reviews of RCTs
Level II	Evidence obtained from at least one well-designed RCT
Level III	Evidence obtained from well-designed controlled trials without randomization (quasi-experimental study)
Level IV	Evidence from well-designed non-experimental studies (case-control, correlational, cohort studies)
Level V	Evidence from systematic reviews of descriptive or qualitative studies
Level VI	Evidence from a single descriptive or qualitative study
Level VII	Evidence from the opinion of authorities and/or reports of expert committees

Critical Appraisal Skills Programme (CASP) tool for assessing qualitative research (35). Non-research records ( $N = 29$ ) were appraised using the Johns Hopkins Nursing Evidence-based Practice tool for Non-Research Evidence Appraisal (31). After critical appraisal was done, all 35 records were included for data extraction and synthesis.

#### Data analysis

Data relevant to the review question were extracted from the included records. The primary author conducted the data extraction and content analysed the extracted data. The second author independently verified both processes in order to improve the rigour of the data analysis. Data display matrices were developed to facilitate data comparison and synthesis. The researchers employed an iterative process by repeating the data extraction and synthesis numerous times, in order to ensure the verification of the results.

#### Results

The 35 records that met the inclusion criteria are presented in the Supplementary file. Two of the records could be classified as level IV evidence, 8 as level VI evidence, and 25 as level VII evidence. Six themes emerged from the data extraction and synthesis. Skills that healthcare providers require for culturally competent communication was the most prominent and most densely represented theme in the literature ( $N = 32$ ), followed by healthcare provider awareness ( $N = 24$ ), healthcare provider knowledge ( $N = 22$ ), culturally competent healthcare systems ( $N = 22$ ), personal characteristics and attitudes ( $N = 13$ ), and models for cross-cultural communication ( $N = 3$ ). Themes are discussed and summarised in Table 2 in the order of frequency with which they appeared in the literature. The literature referred to a range of healthcare professionals, including oncologists, surgeons, and nurses, but most of the sources did not specify the type of healthcare professional involved; hence, the term healthcare provider is used generically.

#### Healthcare provider skills ( $N = 32$ )

This theme encompasses the skills required for culturally competent communication. It addresses actions required for integrating cultural knowledge (5, 36) and knowledge of diverse population health into clinical practice (24). Effective communication skills (11, 18, 37) were most prominently featured in the included literature ( $N = 18$ ). Using simple language (18–42) and checking patient understanding of information given (36, 39–41, 43, 44) were the most cited communication skills.

Managing difference in the patient–provider encounter ( $N = 13$ ) can be challenging. The literature underscored that healthcare providers should avoid stereotyping and generalisations (5, 11, 37, 18, 36, 44, 45).

Skills related to building the patient–provider relationship ( $N = 12$ ) ranged from the significance of the initial

medical encounter (11, 36, 46, 47) to specific relational skills like building rapport (41, 48), gaining patient trust (11, 17, 49), addressing patients appropriately according to their cultural preference (11), and engaging in culturally sensitive communication (50).

The importance of assessment skills were also underscored in the literature (18, 36) and specific assessment skills for conducting a patient assessment beyond the biomedical aspect ( $N = 13$ ) were highlighted (41, 46, 51).

Key findings pertaining to accommodating the patient's family ( $N = 5$ ) included communicating with the patient's extended family (11), investing in and gaining family trust (11, 38), balancing autonomy and dependency when meeting patient and family needs (52), and affording the family the maximum control possible (51). Accommodating religion and spirituality ( $N = 4$ ) by recognising patients' spiritual needs (51), acknowledging religion in the patient's belief system (11, 42), and demonstrating respect for religious beliefs (38) were also identified as key findings.

#### Healthcare provider awareness ( $N = 24$ )

Cultural awareness is an essential part of delivering culturally competent patient–provider communication (46, 53). Contextual awareness ( $N = 11$ ) relates to variables such as the country's socio-political history (41), socio-cultural factors (45), patients' phases of acculturation to the dominant culture (47), and patient demographics in the service area (38, 42, 48, 52, 54).

Self-awareness ( $N = 9$ ) (11, 12, 18, 36) with regard to the provider's own culture (55); cultural beliefs (19); health belief systems (54); spirituality (51); and cultural assumptions, personal biases, and stereotypes (5, 19, 45, 54, 55) is supported by various authors.

Interpersonal awareness ( $N = 5$ ) with regard to inherent power differentials between healthcare providers and patients (41), the interaction between patients and healthcare providers' cultures during the medical encounter (40, 55), and communication differences between cultures (36, 48) was highlighted in the literature.

Awareness of cultural expectations in the healthcare setting ( $N = 5$ ) pertains to the level of family involvement required (1, 44, 52, 54, 56) and the degree of direction expected from healthcare providers which may be more than what typically predominates in Western settings (54).

#### Healthcare provider knowledge ( $N = 22$ )

This theme ( $N = 22$ ) highlights the acquisition of sound factual knowledge and an understanding of various cultural aspects (11). When obtaining this culture-specific knowledge, healthcare providers should be cognizant of intra-cultural differences (5, 36, 44, 52, 57).

Context-specific knowledge ( $N = 9$ ) relates to knowledge of cultural groups seeking services in the provider's clinical setting (11, 18, 36, 47, 52, 58).

The importance of healthcare providers' self-knowledge ( $N = 6$ ) pertaining to their own culture (11, 18, 36, 59),

*Table 2.* Themes and subthemes

Themes	Subthemes	Delineation of the subthemes
Healthcare provider skills ( <i>N</i> = 32)	Communication skills (11, 18, 36) ( <i>N</i> = 18)	Engage in: <ul style="list-style-type: none"> <li>• culturally sensitive communication (1, 5, 43, 49)</li> <li>• culturally congruent communication (5, 11)</li> <li>• clear (11, 44), accurate (11, 44), open (39, 42, 51, 53), flexible (42), and transparent (51) communication</li> <li>• congruent verbal and non-verbal communication (5, 11)</li> </ul> Deliver care that patients understand (43, 57) Deliver culturally and linguistically sensitive services (55) Provide information in the patient's language (44) Learn the language (44) Develop a vocabulary of terms familiar to the patient (44) Provide clear information (48) Use simple language (38–42) Encourage the patient to ask questions (48) Repeat explanations (41) Check patients' understanding of information (36, 39–41, 43, 44) Observe culturally appropriate non-verbal communication etiquette (5)
	Managing difference in the patient–provider encounter ( <i>N</i> = 13)	Avoid stereotyping and generalisations (5, 11, 37, 18, 36, 44, 45) Treat patients equally (38, 42) Avoid making assumptions about patient race, nationality, and language (1) Encourage patients to raise concerns about discrimination (39) Create a culturally safe and caring environment (41, 53) Individualise patient care (45, 53)
	Skills required for building the patient–provider relationship ( <i>N</i> = 12)	Invest time in the beginning (36, 46, 47) Engage the patient (11) Build rapport (41, 48) Gain patient trust (11, 17, 42, 48, 49) Actively engage patient in decision-making (36, 43, 48) Encourage and empower patients to raise trust issues (39) Address patients according to cultural preference (11) Recognise inherent power differentials (11) Be open about own cultural frame of reference (59) Acknowledge own cultural background to patients (1) Respond skilfully to cultural discordance (11)

Table 2 (Continued)

Themes	Subthemes	Delineation of the subthemes
	Ability to conduct a patient assessment (18, 26) beyond the biomedical (N = 11)	Assess patients' specific communication needs (46) Conduct a cultural assessment (40, 46, 51) <ul style="list-style-type: none"> <li>• Active exploration of cultural issues (54)</li> <li>• Invite patients to describe their cultural backgrounds (57)</li> <li>• Explore views on family and community in the healthcare context (57)</li> <li>• Explore cultural (11) and health beliefs (54)</li> <li>• Explore family expectations, feelings, and concerns (51)</li> <li>• Explore level of family involvement required (54)</li> <li>• Determine who the main decision-makers are (patient or family?) (45, 47)</li> <li>• Explore preferences for truth disclosure (1, 36, 54)</li> </ul> Conduct a spiritual assessment (51) Explore religious beliefs (1)
	Accommodating the patient's family (N = 5)	Invest in and gain family trust (11, 38) Communicate with extended family as per patient's directive (11) Balance autonomy and dependency when meeting patient and family needs (52) Afford the family maximum control possible if this is a patient need (51)
	Accommodating religion and spirituality (N = 4)	Recognise patients' spiritual needs (53) Acknowledge the role of religion in the patient's belief system (11, 42) Demonstrate respect for religious beliefs (38)
Healthcare provider awareness (N = 24)	Contextual awareness (N = 11)	Awareness of: <ul style="list-style-type: none"> <li>• country's socio-political history (41)</li> <li>• socio-cultural factors that affect the patient-provider relationship (45)</li> <li>• patients' different phases of acculturation to the dominant culture (47, 56)</li> <li>• patient demographics in the service area (54)</li> <li>• the role of gender and religion in culture (48, 52)</li> <li>• patients' level of education (38, 42)</li> <li>• patients' experiences of discrimination in clinical settings (39)</li> <li>• dominant cultural narratives regarding health and illness (59)</li> <li>• culturally constructed myths about cancer (49)</li> <li>• patients possible combining allopathic and traditional medicine (59)</li> </ul>
	Self-awareness (1, 18, 26) (N = 9)	Awareness of own: <ul style="list-style-type: none"> <li>• culture (55)</li> <li>• cultural beliefs (19)</li> <li>• belief systems (54)</li> <li>• spirituality (51)</li> <li>• own cultural assumptions, biases, and stereotypes (5, 18, 45, 54, 55)</li> </ul>

Table 2 (Continued)

Themes	Subthemes	Delineation of the subthemes
Healthcare provider knowledge (N = 22)	Interpersonal awareness (N = 5)	Interpersonal awareness of: <ul style="list-style-type: none"> <li>• inherent power differentials between patient and provider (41)</li> <li>• interaction between patient and provider's culture (40, 55)</li> <li>• communication differences between cultures (36, 48)</li> </ul>
	Awareness of cultural expectations in the healthcare setting (N = 5)	Awareness of: <ul style="list-style-type: none"> <li>• the level of family involvement required (44, 54)</li> <li>• the role of family in cross-cultural clinical settings (1, 44, 52, 56)</li> <li>• patients' possibly expecting a directive approach from providers (54)</li> </ul>
	Context specific knowledge (N = 9)	Knowledge of: <ul style="list-style-type: none"> <li>• cultural groups attending services in the provider's clinical setting (11, 18, 36, 47, 52, 57)</li> <li>• serviced population's disease profiles, health disparities, and treatment outcomes (36, 37)</li> <li>• cultural health-related needs and health-seeking behaviours (18)</li> <li>• cultural approaches to illness and treatment (45)</li> <li>• cultural meanings of cancer (5)</li> <li>• patients' perception of their illness (36)</li> <li>• influence of culture on how patient interacts with healthcare system (54)</li> </ul>
	Self-knowledge (N = 6)	Knowledge of own: <ul style="list-style-type: none"> <li>• culture (11, 18, 36, 59)</li> <li>• belief system (18)</li> <li>• own biases and stereotypes (5, 11, 18, 54)</li> </ul>
	Knowledge of patient's culture (N = 5)	Knowledge of patients': <ul style="list-style-type: none"> <li>• health belief systems (11, 39, 44)</li> <li>• traditional health system (44)</li> </ul> Knowledge of: <ul style="list-style-type: none"> <li>• the role of gender and family in the decision-making (44, 47)</li> <li>• preferences regarding language used to discuss cancer (1)</li> <li>• non-verbal communication standards (1)</li> </ul>
	Knowledge of broader contextual factors (N = 5)	Knowledge of: <ul style="list-style-type: none"> <li>• racism, sexism, and ageism (19, 62)</li> <li>• socio-political barriers to accessing healthcare (5, 11, 18)</li> <li>• the impact of past and present racism (18)</li> <li>• the role of gender, age and role expectations in the communication process (5)</li> <li>• socio-historical cultural context (5)</li> <li>• socio-cultural differences between self and patient (18)</li> </ul>

Table 2 (Continued)

Themes	Subthemes	Delineation of the subthemes
Culturally competent healthcare systems ( <i>N</i> = 22)	Characteristics of culturally competent healthcare systems ( <i>N</i> = 6)	<ul style="list-style-type: none"> <li>• are responsive to individual needs and to how cultures are perceived (18, 49)</li> <li>• promote and facilitate effective patient-centred communication (18)</li> <li>• respect cultural differences, and support effective care for diverse populations (18)</li> <li>• provide ethnic-specific services (5)</li> <li>• convert an awareness of disease prevalence into practices and policies (37)</li> <li>• develop and implement policies to support effective cross-cultural communication (18, 53)</li> <li>• link with culturally competent agencies and community organisations that provide bilingual and bicultural navigation, promotions, and community health outreach services (5)</li> <li>• have adequate support services (53)</li> </ul>
	Strategies employed by culturally competent healthcare systems ( <i>N</i> = 17)	<ul style="list-style-type: none"> <li>• use patient navigators (11, 24, 47, 48, 60, 61)</li> <li>• use professional translators (1, 5, 17, 39, 44, 45, 48, 54, 57, 59)</li> <li>• use of culturally sensitive print, visual, and audio-visual media and electronic communication (39, 43, 48)</li> <li>• use images to assist providers when discussing cancer with patients (41)</li> <li>• monitor patient characteristics (39)</li> <li>• translate written communications (45)</li> <li>• provide language-concordant encounters (39)</li> <li>• provide patient-centred care (60)</li> <li>• consult communities on cultural needs (41)</li> <li>• integrate community resources into cancer care (5)</li> <li>• display images of people from cultural groups attending the service (41)</li> <li>• have ethnically similar staff visible (41)</li> </ul>
Healthcare providers' personal characteristics and attitudes ( <i>N</i> = 13)	Healthcare providers' personal characteristics ( <i>N</i> = 11)	<ul style="list-style-type: none"> <li>• individual sensitivity (1, 18, 46, 61)</li> <li>• humility (1, 62)</li> <li>• empathy (18, 41, 57, 62)</li> <li>• curiosity (62)</li> <li>• compassion (18)</li> <li>• sincerity (19, 60)</li> <li>• tolerance (19)</li> <li>• acceptance (53)</li> <li>• authentic and respectful at all times (11, 19, 53, 57, 60)</li> <li>• value others (53)</li> </ul>

Table 2 (Continued)

Themes	Subthemes	Delineation of the subthemes
	Healthcare providers' attitudes (N = 13)	<ul style="list-style-type: none"> <li>• take responsibility for cultural aspects of health and illness (45)</li> <li>• take responsibility for combating discrimination in healthcare settings (45)</li> <li>• willingness to learn from patients (11)</li> <li>• openness to change and growth (53)</li> <li>• cultural sensitivity (1, 45, 53)</li> <li>• willingness to listen (53)</li> <li>• respect for cultural diversity, for the patient's culture and their cultural values (5, 11, 39, 42, 45, 52, 54, 62)</li> <li>• appreciation of different health belief systems (62)</li> <li>• willingness to explore culture with individual patients (36)</li> <li>• validate different cultures (57)</li> <li>• continual self-examination and self-reflection to examine one's own values and assumptions (18, 19, 53)</li> <li>• willingness to adjust behaviour and attitudes (36)</li> <li>• reflection on own interaction with cultural groups in the clinical setting (36)</li> </ul>
Models of effective cross-cultural communication (N = 3)	Kleinman's questions (17, 57) (N = 2)	What do you think has caused your problem? Why do you think it started when it did? What do you think your sickness does to you? How severe is your sickness? Will it have a short or long course? What kind of treatment do you think you should receive? What are the most important results you hope to receive from this treatment? What are the chief problems your sickness has caused for you? What do you fear most about your sickness?
	The LEARN Model (36, 57) (N = 2)	Listen with sympathy and understanding to the patient's perception of the problem Explain your perceptions of the problem Acknowledge and discuss the differences and similarities Recommend treatment Negotiate treatment
	The BELIEF Model (57) (N = 1)	Beliefs about health (What caused your illness/problem?) Explanation (Why did it happen at this time?) Learn (Help me to understand your belief/opinion.) Impact (How is this illness/problem impacting your life?) Empathy (This must be very difficult for you) Feelings (How are you feeling about it?)
	The Four Habits Model of Highly Effective Clinicians (36) (N = 1)	Invest in the beginning Elicit the patient's perspective Demonstrate empathy Invest in the end

belief system (18), and biases and stereotypes (5, 11, 18, 54) is emphasised.

Similarly, knowledge of patients' cultures ( $N=5$ ), including their health belief systems (11, 39, 44), their traditional health systems (44), their processes of decision-making (1, 44, 47), and their standards of etiquette (1, 44), is underscored in the literature.

Knowledge of the broader contextual variables ( $N=5$ ) centres on the socio-political barriers to accessing healthcare (11), the socio-historical cultural context and its influence on patients' and families' view of cancer (5), and the socio-cultural differences between the self and patient and its impact on patient-provider communication (18).

#### *Culturally competent healthcare systems ( $N=22$ )*

Culturally competent communication extends beyond the individual provider to the healthcare system. Culturally competent healthcare systems are agents for the provision of appropriate patient care for diverse population groups that extend beyond addressing individual patient needs, to policy and community level (5, 37, 39, 43). Specific organisational strategies for culturally competent communication are well-represented in the literature. The most common strategies were the use of patient navigators (11, 24, 47, 48, 60, 61) and professional translators (1, 5, 11, 39, 41, 44, 45, 48, 54, 56, 57, 59).

#### *Healthcare providers' personal characteristics and attitudes ( $N=13$ )*

This theme highlights healthcare providers taking responsibility for cultural aspects of health and illness, and for combating discrimination in healthcare settings (45). The literature provided an extensive list of healthcare provider personal characteristics and attitudes that can facilitate culturally competent communication which is featured in Table 2. The most prominently featured healthcare provider attitude pertained to demonstrating respect for cultural diversity and patients' cultural values (5, 11, 39, 42, 45, 52, 54, 62).

#### *Models of effective cross-cultural communication ( $N=3$ )*

Models of effective cross-cultural communication ( $N=3$ ) have been cited in some of the documents included in this integrative review. Kleinman's questions (17, 57), the LEARN Model (36, 57), the BELIEF Model (57), and the Four Habits Model of Highly Effective Clinicians emerged as key findings with regard to this theme.

### **Discussion**

The aim of the integrative review was to determine how culturally competent patient-provider communication is best delivered to adult patients diagnosed with cancer. Several important themes emerged about how this can be achieved. Despite the exhaustive nature of the integrative

review a number of limitations remain. Only databases available at the university where the searches were conducted were used. Interlibrary loans were then used to obtain other documents. Two key documents could not be used because they could not be obtained by the university libraries. Most of the documents have been evaluated as level VII evidence ( $N=25$ ), the lowest level of evidence. Eight of the documents fulfil the criteria for level VI evidence, and only two of the documents could be evaluated as level IV evidence.

There are a number of possible reasons for the lack of research at higher levels of evidence. The concept of cultural competence first appeared in the social work and counselling psychology literature in 1982 (30). A report issued by the US Department of Health and Human Services in 2001 highlighted that despite widespread policy recognition of the important role that cultural competence plays in facilitating accessible and effective healthcare for culturally diverse populations, policymakers were still in the early stages of defining cultural competence in a manner that facilitates empiricism and implementation (63). This lack of consensus on defining this concept was apparent in this report almost two decades after the concept first appeared in the literature. More recent literature still reports that despite the proliferation of cultural competency frameworks and models since their inception, there is still no one authoritative framework available (64, 65). There are a number of consonant concepts available such as culturally appropriate care, culturally sensitive care, and so forth, which further complicate the cultural competence theoretical and applied landscape (30, 64). A lack of uniformity in policy making with regard to comprehensive versus specific approaches to cultural competence has resulted in a burgeoning of ideas and methodologies about what constitutes cultural competence (63). The literature also indicates a lack of agreement on how best to implement cultural competence (65), and research on interventions for improving cultural competence in healthcare tends to lack methodological rigour (64). Hence, despite the recognition of how beneficial cultural competence can be in rendering effective healthcare services to diverse population groups, the lack of uniformity on conceptual, intervention, and policy fronts results in a myriad of disparate information. It is therefore hypothesised that while there is extensive literature on cancer health disparities and use of 'cultural competence' as a means of addressing these disparities (25, 66–68), research on how best to deliver culturally competent patient-provider communication to patients diagnosed with cancer is sparse owing to the aforementioned challenges associated with the concept of cultural competence.

Despite these challenges, the results of this integrative literature review provided useful insights for clinical practice. Engaging in culturally competent communication requires 'communicating with awareness and knowledge

of healthcare disparities and understanding that socio-cultural factors have important effects on health beliefs and behaviours, as well as having skills to manage these factors appropriately' (20). The first three themes clearly illustrate this definition. The personal characteristics and attitudes required for culturally competent communication also emerged from the literature. Furthermore, the findings extend from the individual provider to emphasising culturally competent healthcare systems and models for culturally competent communication that can guide practice. The literature highlights the importance of this extension by emphasising that cultural competence should be addressed at policy, organisational, and systems levels (41). The information was categorised into various themes and subthemes to facilitate ease of reference and application in clinical practice. However, the findings related to these themes should be treated with caution as the results are based mostly on low-level evidence (Level VII) (32), indicating the lack of research using methodologies linked to high levels of evidence in this study area. In addition, all the studies were international and only one of the studies focused on an African refugee population albeit in the context of the US. The unique African setting necessitates and could greatly benefit from research on culturally competent patient-provider communication at higher levels of evidence.

### Conclusions

The findings of the integrative literature review have important practice implications. The themes that emerged during the integrative review process provide some insight into the 'how' of delivering culturally competent patient-provider communication to adult patients diagnosed with cancer. The grave need for scientifically rigorous research yielding higher levels of evidence in the field of cancer and culturally competent patient-provider communication is emphasised by the lack of quality evidence for all the themes that were presented in this integrative literature review.

### Authors' contributions

Ms Brown has made substantial contributions to the conception and design of the work; the acquisition, analysis, and interpretation of data for the work; drafting the work; final approval of the version to be submitted to the journal; and has agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Dr ten Ham-Baloyi has made substantial contributions to the design of the work; the analysis and interpretation of data for the work; revising the work critically for important intellectual content; final approval of the version to be published; and has agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or

integrity of any part of the work are appropriately investigated and resolved.

Prof van Rooyen has made substantial contributions to the conception and design of the work; revising it critically for important intellectual content; final approval of the version to be published; and has agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Prof Aldous has made a substantial contribution to the conception and design of the work; revising it critically for important intellectual content; final approval of the version to be published; and has agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Dr Marais has made a substantial contribution to the conception and design of the work; revising it critically for important intellectual content; final approval of the version to be published; and has agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

### Ethics approval

Ethics approval for the PhD study was obtained from the Biomedical Research Ethics Committee (BREC) of the University of KwaZulu-Natal (UKZN) where the PhD study is registered. However, this is an integrative literature review and there were no human subjects involved in this article.

### Conflicts of interest and funding

The authors do not have any conflicts of interest to declare.

### Paper context

Patient-provider communication in cancer care as well as cross-cultural clinical settings is known to be challenging. This article provides information on how healthcare providers can deliver culturally competent care to cancer patients when working in cross-cultural clinical settings. The integrative literature review was performed to explore existing evidence and revealed that more rigorous research yielding higher levels of evidence is needed in the field of culturally competent patient-provider communication with cancer patients.

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Supplementary File: Summary of 35 Included Records

<b>Author and Year of Publication</b>	<b>Type of Study</b>	<b>Summary of Findings</b>	<b>Level of Evidence</b>
Atkin et al. 2014	Qualitative study	Practitioners, despite a commitment to sensitive care, struggle to reconcile individual behaviour with what they think they know about South Asian cultures which creates misunderstandings, leading to poor practice. Strategies for cultural competence: self-awareness; awareness of cultural practices; demonstrating sensitivity; integrating cultural competence into clinical practice; challenging beliefs about cultures.	Level VI
Barclay et al. 2007	Literature study	Reported on the following strategies: awareness of a possible need for the provider to take a more directive role, of patient demographics in service area, of own health belief system and own cultural biases; accommodating patients that require family involvement; knowledge of own cultural biases. Urged active exploration of cultural issues with patients and preferences for truth disclosure. Proposed demonstrating respect; recognising patients' health beliefs; and using professional translators.	Level VII
Beyene 1992	Case study	Key strategies reported: understand and accommodate the role of the family; allow family participation in care if required by culture; do not misjudge level of acculturation with dominant culture; demonstrate warmth; be culturally sensitive to beliefs and practices; use professional translators.	Level VI
Chambers 2008	Book chapter	Strategies reported included: awareness of dominant cultural narratives and of patients' tendency to mix allopathic and traditional medicine; knowledge of own culture; knowledge of the community's clinical experience; openness about own cultural frame; identify redressive actions in a community; use professional translators; locate and use cultural informants.	Level VII

<b>Author and Year of Publication</b>	<b>Type of Study</b>	<b>Summary of Findings</b>	<b>Level of Evidence</b>
Chaturvedi et al. 2014	Case study	Highlighted importance of awareness of patient education levels and the role of culture in health belief systems. Emphasised that culture shapes patients' interaction with the healthcare system. Strategies included: effective communication; explore patient and family perspectives; respect religious beliefs; enhance patient trust; treat patients equally; simplify information.	Level VII
Cohen & Palos 2001	Literature study	Defined key concepts and summarised available guidelines to assist with providing culturally competent nursing care. Concluded that becoming culturally competent begins with understanding terms and concepts that are essential in developing cultural awareness, knowledge and skills. Emphasised sensitivity to language and the history of the development of some labels, assessing communication needs and conducting cultural assessments.	Level VII
Coughlin 2014	Literature study	Reported on the roles of cultural competency, patient trust, and health literacy in the oncology setting. Highlighted the need for culturally competent lung cancer patient navigators from the point of diagnosis to the initiation and completion of treatment, including cancer staging.	Level VII
Dein 2006	Book chapter	Emphasised the importance of: awareness of own culture, interaction of patient and provider culture, own stereotypes; providing culturally and linguistically sensitive services.	Level VII
Die Trill & Holland 1993	Case study	Cancer was used as a model to highlight major cultural issues that should be considered in order to increase cultural sensitivity in the medical setting: family function, sex roles, language, disclosure of disease-related information, pain, attitudes towards illness and health practices, immigration, region, autonomy versus dependency, and death and bereavement. Emphasised avoiding cultural stereotyping when being culturally sensitive and being respectful.	Level VI

<b>Author and Year of Publication</b>	<b>Type of Study</b>	<b>Summary of Findings</b>	<b>Level of Evidence</b>
Epner & Baile 2012	Case study	Argued that the categorical or multicultural approach to cultural competence results in stereotypical thinking. The cross cultural approach focuses on foundational communication skills, awareness of cross-cutting cultural and social issues, and health beliefs that are present in all cultures and offers a patient-centred alternative. Highlighted various models of effective cross-cultural communication and negotiation and the key elements of patient-centred care.	Level VII
Huang et al. 2009	Qualitative study	Explored the social construction of cultural issues and found that previous experiences with people from other cultures and organisational approaches to culture and cultural care often influenced nurses' views and understandings of culture and cultural mores and their beliefs, attitudes and behaviours in providing cultural care.	Level VI
Kagawa-Singer et al. 2010	Literature study	Proposed strategies for reducing health disparities in cancer care included: acknowledging own personal assumptions and biases; gaining an understanding of the cultural meaning of cancer; recognising culture of both patient and provider; awareness of cultural variations within cultures; integrating cultural knowledge into communication; providing information in a respectful manner to the designated receiver; using culturally appropriate nonverbal communication etiquette; engaging in congruent verbal and nonverbal communication; integrating community resources into cancer care; using professional translators; providing ethnic-specific services.	Level VII
Kagawa-Singer 2013	Book chapter	Proposed cultural competence as a critical skill set for improving quality of health care, improving equity in the availability of healthcare and eliminating health disparities among population groups with regard to cancer care. Defined culture and cultural competency and discussed culturally based communication strategies to facilitate building trust between patient, family and provider with a view to negotiating mutually agreed upon goals for treatment.	Level VII

<b>Author and Year of Publication</b>	<b>Type of Study</b>	<b>Summary of Findings</b>	<b>Level of Evidence</b>
Kreps 2006	Literature study	Provided an overview of cancer-related health disparities in the US and outlined communication strategies for reducing health disparities: minimise bias; demonstrate respect; make patients active participants; sensitive and adaptive communication to overcome health literacy barriers; use appropriate language; check patient understanding; use culturally sensitive print, audiovisual and electronic communication; formulate and implement policies to support effective cross-cultural communication.	Level VII
Lavizzo-Mourey & Mackenzie 1995	Literature study	Acknowledged the critical role of culture and the importance of establishing guidelines for culturally competent medical care. Advocated having knowledge of: health-related cultural factors; the incidence and prevalence of diseases in the population; treatment outcomes peculiar to that population. Cautioned against blanket racial classifications; advocated integrating knowledge of diverse population health into clinical practice and converting an awareness of disease prevalence into practices and policies.	Level VII
Lichtveld et al. 2012	Book chapter	Focused on the role of cultural competence in addressing health disparities and proposed strategies for creating a culturally competent cancer workforce. Highlighted being aware of phases of acculturation and advocated knowledge of: the patient's culture, ethnic and geographic differences; processes of decision-making in different cultures; role of culture in health belief systems. Emphasised the significance of first medical encounters and the role and effectiveness of patient navigators.	Level VII
Longo & Slater 2013	Case study	Illustrated the challenges of providing culturally-competent. Proposed strategies for culturally competent care included: recognition of spiritual and cultural needs; understanding that patients and families may respond differently to the dominant cultural expectation; conducting cultural and spiritual assessments of patients and families as part of the psychosocial assessment; maintaining open communication; providing family with maximum control possible; maintaining hope.	Level VII

Author and Year of Publication	Type of Study	Summary of Findings	Level of Evidence
Matthews-Juarez & Juarez 2011	Literature study	Proposed practices for reducing health disparities and improving cultural competence included: awareness of personal biases and stereotypes; cultural knowledge of health-related needs; knowledge of own belief system, own culture and patients' culture, own stereotypes and biases, cultural variations within cultures; knowledge of the impact of sociocultural differences on patient-provider interactions; effective assessment and communication skills; responsiveness to individual needs; effective patient-centred communication; respect for cultural differences; need for policies.	Level VII
Mitchell 1998	Literature Study	Reported on the cross-cultural aspects of cancer disclosure. Strategies: awareness of culturally constructed myths about cancer; explore patients' disclosure preferences before diagnostic testing; ensure that MDT is aware of disclosure preferences; be sensitive regarding terms used when discussing cancer.	Level VII
Moore et al. 2012	Quantitative study	Found that: interpersonal treatment explained the greatest amount of patient satisfaction; adequate communication that addresses relevant patient needs and concerns during all medical encounters improves patient satisfaction; patient-centred care can build trusting relationships. Recommended respectful communication.	Level IV
Mullin et al. 1998	Case study	Focused on cross-cultural patient-provider difficulties and how this interfered with quality of care. Recommendations to improve quality of treatment in cross-cultural settings included learning the patient's language or developing a vocabulary of terms that are familiar to patients, not stereotyping, using professional translators.	Level VII
Muñoz-Antonia 2014	Conference paper	Proposed that culturally competent care should become the mandate of all providers and specifically urged oncology providers to become more familiar with disease patterns and cultural health belief systems that impact cancer care. Highlighted awareness of cultural differences, communicating in an understandable manner and demonstrating respect.	Level VII

Author and Year of Publication	Type of Study	Summary of Findings	Level of Evidence
Murphy et al. 2010	Literature study	Communication between provider and patient is proposed as important for reducing cancer care disparities along the disease trajectory especially as research cited in the article demonstrated that there is a disconnect between how providers think they are interacting and how patients are perceiving the interaction. Specific strategy - patient navigation.	Level VII
Ngo-Metzger 2006	Literature study	Reviewed the literature focusing on the following five domains of culturally competent care: patient-provider communication, respect for patient preferences and shared decision-making, experiences leading to trust or mistrust, experiences of discrimination, linguistic competency. Advocated culturally competent care as a strategy for reducing or eliminating ethnic and racial health disparities.	Level VII
Pârvu et al. 2013	Qualitative study	Reported that participants had particular explanations and meanings of illness which sometimes negatively affected coping. Suggestions for culturally competent practice: awareness of personal biases and socio-cultural factors; knowledge of cultural approaches to illness and treatment; ability to determine key decision-makers, avoid generalizations. Providers should take responsibility for: cultural aspects of health and illness, combating discrimination in healthcare settings and be culturally sensitive and respectful of cultural values	Level VI
Pesquera et al. 2008	Literature study	Reported on cancer health disparities in the US and the role of culturally competent care in reducing these disparities. Detailed strategies for improving cultural competence with specific reference to building cultural awareness, knowledge and skills are outlined. Discussed cultural competence standards and improving cross-cultural communication.	Level VII
Pierce 2008	Literature study	Proposed culturally competent practice strategies included: being self-aware; having knowledge of different cultures, own culture, patient's culture, patient's health belief system, socio-political barriers to accessing healthcare; recognising inherent power differentials; engaging the patient; communicating; demonstrating respect; gaining patient	Level VII

Author and Year of Publication	Type of Study	Summary of Findings	Level of Evidence
		and family trust; avoiding stereotyping /generalisations; clear and accurate communication; communicating with the patient's extended family; congruent verbal and nonverbal communication; gaining access to and using patients' natural support systems to help them; using a patient navigator.	
Rollins & Hauck 2015	Case study	Described the impact of culture on delivering bad news to patients and proposed a patient-centred approach to delivering bad news. Reported that patients vary in the preferences for receiving bad news both within and across cultures. Authors combined the SPIKES and Kleinman's ethnographic models and these models' inherent strategies to address these preferences.	Level VI
Shahid et al. 2013	Qualitative study	Reported on communication challenges between health professionals and Aboriginal people with cancer. Found that Aboriginal people are marginalised and mistrust the health system. Proposed improving communication by heeding language, communication style, use of medical terminology and cross-cultural differences in time. Strategies included: avoid medical jargon, repeat explanations, use professional translators, use images to explain cancer.	Level VI
Song et al. 2014	Quantitative study	Found that socio-cultural factors are associated with patient-provider communication. Reported that providers need to be aware of patient education levels, engage in behaviours that enhance trust, treat patients equally, respect religious beliefs, and reduce the difficulty level of the information.	Level IV
Surbone 2004	Editorial	Focused on culture and cultural competence in oncology. Defined culture and argued the important role of culture in defining our identity. The complexity of cultural competence and the acquisition of knowledge, skills and attitudes to facilitate effective cross-cultural communication in clinical settings were argued.	Level VII

<b>Author and Year of Publication</b>	<b>Type of Study</b>	<b>Summary of Findings</b>	<b>Level of Evidence</b>
Surbone 2008	Literature Study	Emphasised the role of culture in oncology communication. Proposed that cultural competence can improve therapeutic outcomes and decrease health disparities. Outlined the knowledge, skills, cultural aspects providers need to be aware of and attitudes required in cross-cultural oncology settings.	Level VII
Surbone 2010	Editorial	Emphasised cultural preferences for truth-telling and the changing landscape in this regard. Proposed cultural competence as a skill set that reduces the likelihood of cross-cultural misunderstanding; that enables negotiation of mutually acceptable goals of treatment with patients and families cross-culturally, and facilitates relationships built on trust and mutual respect.	Level VII
Surbone & Baider 2013	Case study	Discussed the ethical value and issues that can arise in the cross-cultural medical setting such as diverse attitudes and practices of truth-telling, family roles, end-of-life issues and caregiving practices. Defined and discussed cultural competence and its components.	Level VI
Thomas et al. 2010	Book chapter	Proposed communication strategies included: be aware of nonverbal communication differences, gender, religious issues; build trust; build rapport; use print or visual media; attend to the patient's expectations, feelings and concerns; make patients active participants; give clear information; encourage questions; use professional translators; use patient navigators.	Level VII

## **Part 2: Conducting Focus Groups with the Healthcare Providers**

The second part of this study addresses the second requirement for evidence-based practice, namely that of accessing clinical expertise. Following the integrative literature review, it was important to gather information from the healthcare providers who treat Zulu patients. Focus groups were conducted with the healthcare professionals. The purpose of these focus groups was to gather data concerning the approach that healthcare providers take when discussing the diagnosis, treatment and prognosis of osteosarcoma with Zulu patients. The focus group interview questions also accessed the cultural aspects of involved in the management of osteosarcoma. Part two consists of three manuscripts. The data gathered from the focus groups interviews were rich and provided thick descriptions that could not be housed in one paper. Following consultation with qualitative research experts, it was decided that the data was too much for one paper and hence three papers were developed. Two of these papers have been submitted for publication and the third paper will be submitted once these have been accepted for publication.

Chapters three, four, and five cover three distinct areas of communication. Chapter three highlights the strategies used and the challenges experienced when communicating the diagnosis of osteosarcoma to Zulu patients. Chapter four focuses on discussing treatment of osteosarcoma with Zulu patients and highlights the cultural factors that are to be considered during this discussion. Strategies for responding to these cultural factors are also explicated in this chapter. Chapter five provides an account of the strategies used and the challenges experienced when communicating about prognosis to Zulu patients. This part of the research project addresses the limitation of low level evidence highlighted in Chapter two. The evidence derived from the focus group interviews can be classified as Level VI evidence. The chapters are presented in the format of the journal that the work was or will be submitted to.

**Chapter 3: Strategies and challenges for communicating the diagnosis of cancer in cross-cultural clinical settings—Perspectives from South African healthcare professionals**

Brown O., Goliath V., Aldous C., Van Rooyen D., Marais LC

**Submitted to the Journal of Psychosocial Oncology**

## **Strategies and challenges for communicating the diagnosis of cancer in cross-cultural clinical settings—Perspectives from South African healthcare professionals**

### **Abstract**

Communicating the diagnosis of cancer in cross-cultural clinical settings is a complex task. This qualitative research article describes the content and process of informing Zulu patients in South Africa of the diagnosis of cancer, using osteosarcoma as the index diagnosis. We used a descriptive research design with census sampling and focus group interviews. We used an iterative thematic data analysis process and Guba's model of trustworthiness to ensure scientific rigour. Our results reinforced the use of well-accepted strategies for communicating the diagnosis of cancer. Additionally, new strategies emerged which may be useful in other cross-cultural settings. These strategies included using the stages of cancer to explain the disease and its progression and instilling hope by using a multidisciplinary team care model. We identified a number of patient, professional and organisational factors that complicate cross-cultural communication. We conclude by recommending the development of protocols for communication in these cross-cultural clinical settings.

Keywords: cancer; patient-provider communication; culture; cultural competence; cross-cultural settings

Communicating the diagnosis of cancer is a daunting (Baile et al. 2000; Bennett & Alison, 1996; Fallowfield & Jenkins, 2004; Walsh, Girgis, & Sanson-Fisher, 2010) and critical communication task as it sets the stage for the patient's cancer journey (Thorne et al., 2009). Performing this task in cross-cultural clinical settings adds to its complexity (Gao, Burke, Somkin, & Pasick, 2009). As culture shapes health-related values and help-seeking behaviours (Dein, 2004; Kagawa-Singer, Valdez Dadia, & Surbone, 2010); an awareness of its influence must be integrated into this communication when navigating cross-cultural barriers. The skills of culturally competent communication are a necessity for healthcare professionals (HCPs) working in situations where differences in languages and cultural contexts abound, and where the need to bridge medical and traditional health belief systems is a daily reality.

In this study, we explored communicating the diagnosis of cancer in a South African context, specifically with the Zulu people from the predominantly rural South African province of KwaZulu-Natal (See Figure 1: Map of South Africa). The Zulu ethnic group consists of indigenous people who speak isiZulu, one of South Africa's 11 official languages. This province has an overall population of 10.9 million (of a total South African population of 54 956 900 million), the majority of which is classified as Zulu (Statistics South Africa, 2014). (Exact statistics not available).



Figure 1: Map of South Africa

We chose to focus our investigation on communication between HCPs and Zulu patients with one index cancer diagnosis: osteosarcoma. Osteosarcoma is the most common primary cancer of bone (Ritter, 2010), and the complexity of its treatment necessitates a multi-disciplinary approach. Previous studies from our centre have found that patients with osteosarcoma typically present late for treatment due to misdiagnosis at community health centres (CHCs) or district hospitals (Ferreira & Marais, 2012). Furthermore, observations from clinical practice suggested that patients used several psychological coping strategies including denial and underestimation of the seriousness of the condition. These observations

also highlighted Zulu patients' preference to exhaust traditional healing options before seeking Western medical assistance. In addition, an integrative literature review highlighted the need for scientifically rigorous research with regard to culturally competent communication regarding cancer.

Our first aim of the study was to provide an account of the content and process of informing Zulu patients of a diagnosis of osteosarcoma. The second aim was to investigate how this account may inform improved practice when HCPs communicate the diagnosis of cancer to Zulu patients. The third aim was to explore whether this investigation might add to the body of knowledge regarding communication of sensitive information in cross-cultural clinical settings. This study is part of a larger project and patients will also be interviewed to gather their perspectives of the communication processes.

## **Method**

### **Research Design and Method**

Ours was a qualitative descriptive study using semi-structured focus group interviews to gather data. The interview schedule was piloted to ensure that a broad range of data was being elicited for the purposes of the study. Additionally, iterative questioning and probing contributed to eliciting rich data and verifying information. Interview questions focused on - approaches that HCPs take when discussing osteosarcoma diagnoses with Zulu patients and the cultural considerations pertaining to this discussion.

### **Participants, Sampling, and Data Collection**

We conducted our study at a tertiary hospital in Western KwaZulu-Natal. The hospital forms part of the national public health system that serves more than 80% of the South African

population. This system provides care to patients who do not have sufficient economic resources to access private healthcare (Benatar, 2013; Keeton, 2010).

The hospital's Tumour, Sepsis and Reconstruction Unit (TSR), dedicated to the treatment of musculoskeletal tumours, employs a multidisciplinary team (MDT) approach to managing patients diagnosed with osteosarcoma. The MDT consists of orthopaedic consultants and registrars; nurses from the orthopaedic and oncology outpatient clinics and wards; and allied health professionals including dietitians, occupational therapists, physiotherapists, social workers, and clinical psychologists. All these members of the MDT were invited to participate in the study. All those that were available when the focus group interviews were conducted participated—a total of 23 HCPs—hence census sampling was used. Three nurses, a social worker and a clinical psychologist were not able to participate due to other demands. Participation was voluntary, and written informed consent was obtained from all participants. Demographic information regarding participants is presented in Table 1. Four Zulu healthcare professionals participated in the study. That the majority of the participants were not Zulu is an accurate reflection of the fact that patient-provider encounters are largely culturally discordant at this tertiary hospital.

The second author (a PhD-level social worker experienced in qualitative data gathering who previously had no prior contact with the participants) conducted three focus groups at the hospital study site; these interviews ranged in duration from 54 to 95 minutes. Due to scheduling conflicts and for the purposes of eliciting discipline specific information, the distinctive groups of professionals were interviewed separately. Each focus group discussion was tape recorded and transcribed verbatim by an independent transcriber with no prior knowledge of the participants. Anonymity was ensured through de-identification using codes.

Table1: Focus group demographic information (n=23)

Orthopaedic consultants and registrars	n=9
Registered nurses from orthopaedic wards, orthopaedic clinic, oncology clinic and pain service	n=5
Allied health professionals (physiotherapists, occupational therapists, dieticians, social worker)	n=9
Gender	
Males	n=8
Females	n=15
Ethnic Group (South Africa)	
White	n=13
Indian	n=4
African (Zulu)	n=4
Coloured	n=2

### **Data Analysis and Trustworthiness**

We approached the data using a well-established form of thematic analysis that consisted of identifying, analysing, and reporting patterns (Braun & Clarke, 2006). We used Guba's four-criterion model of trustworthiness (Lincoln & Guba, 1985; Shenton, 2004; Whittemore, Chase, & Mandle, 2001) to ensure rigour.

### **Ethical Approval**

Ethical approval was obtained from the Biomedical Research Ethics Committee at the University of KwaZulu-Natal.

## **Results**

The data suggested that HCPs use 5 distinct strategies to communicate the diagnosis of cancer, in this case osteosarcoma, to Zulu patients. They also noted that several factors complicate communicating the diagnosis of osteosarcoma to Zulu patients. Several participants reported that they experienced the focus group participation as transformative (De Laine, 2000) as they were able to reflect on their current practice, share challenges with and learn from fellow participants.

### **Strategies for communicating the diagnosis of osteosarcoma**

The strategies for communicating the diagnosis of osteosarcoma to Zulu patients are outlined in Table 2.

Table 2: Strategies for communicating the diagnosis of osteosarcoma

<b>Sub-theme</b>	<b>Strategies</b>
Set the stage for truth-telling	<p>Start discussion right from the beginning</p> <p>Assess how much the patient knows</p> <p>Ask patients about their disease process</p> <p>Warn patients a few times about possible cancer diagnosis</p> <p>Give patients incremental information as the diagnostic process unfolds</p> <p>Inform patients of the reasons for diagnostic tests</p> <p>When diagnosis is confirmed, warn patient before communicating the diagnosis</p> <p>Warn patient by reminding patient of earlier conversations of possible diagnosis</p> <p>Confirm diagnosis only once patient has been warned</p> <p>Maintain hope</p>
Engage in patient-centred communication	<p>Build a relationship with the Zulu patient</p> <p>Spend time with the patient</p> <p>Offer the patient support</p> <p>Demonstrate a personal interest in the patient</p>

<b>Sub-theme</b>	<b>Strategies</b>
	<p>Assess and address patient needs, fears and concerns, and coping</p> <p>Respond to patient questions about the diagnosis</p> <p>Gauge patients' reactions</p> <p>Manage denial by</p> <ul style="list-style-type: none"> <li>acknowledging that the diagnosis is difficult to accept</li> <li>reinforcing the diagnosis</li> <li>helping patients to accept the diagnosis</li> </ul>
Engage in culture-centred communication	<p>Take responsibility for improving communication</p> <p>Include some basic isiZulu phrases in conversations</p> <p>Demonstrate an understanding of Zulu cultural health beliefs</p> <p>Reassure patients that their diagnosis is</p> <ul style="list-style-type: none"> <li>not due to anything that they have done</li> <li>not a punishment</li> <li>not due to bewitchment</li> </ul> <p>Demonstrate a genuine interest in patients' culture</p>

<b>Sub-theme</b>	<b>Strategies</b>
	<p>Ask patients questions about</p> <ul style="list-style-type: none"> <li>their cultural and religious practices</li> <li>their understanding of the aetiology of the condition</li> <li>how they want to manage the condition</li> <li>their cultural health beliefs</li> </ul> <p>Offer patients the best care possible regardless of language discordance</p>
Facilitate understanding of the diagnosis using visual aids	Use images, pictures and information brochures
Facilitate understanding by using the stages of cancer	<p>Educate patients regarding their stage of the disease</p> <p>Educate patients about the effects of cancer in every stage</p>
Facilitate understanding of the diagnosis using metaphors	<p>Use metaphors to explain concepts like cells, organs, tumours and metastases</p> <p>Use patient-initiated metaphors</p>
Check patient understanding	<p>Repeat information several times</p> <p>Check what patients remember from previous explanations</p>
Address language barriers	Use language that patients can understand

<b>Sub-theme</b>	<b>Strategies</b>
	<p>Avoid using medical jargon</p> <p>Use professional or experienced translators</p>
Instil hope through MDT involvement	<p>Reassure patients of continued involvement of the multidisciplinary team</p> <p>Differentiate the different problems that would be addressed</p> <p>Explain how the different problems would be addressed</p> <p>Maintain hope regardless of disease stage</p>

### **Set the stage for truth-telling.**

HCPs suggested that the diagnosis discussion should be started right at the beginning in order to assess how much patients know. This assessment entailed asking patients about their disease process.

*So it often means having to break down what that means and starting right at the beginning: when did you first get sick, how did it progress, where did you go for treatment and this is what cancer means firstly a... So it is a discussion that we start on first contact with patient...*

HCPs proposed that patients should be warned on multiple occasions regarding the possibility of a cancer diagnosis during the diagnostic work-up. Information should be provided incrementally as the diagnostic process unfolds to reduce patients' emotional shock. Patients should be informed of the reason for diagnostic tests. Before confirming the diagnosis, patients should be warned by reminding them of earlier conversations regarding diagnostic possibilities. HCPs emphasised maintaining hope while setting the stage for truth-telling.

*...what I think is important is that they are part of the planning process from the beginning... I think that the idea of cancer or malignancy should be put into their minds from an early stage, that that is something that you are working up or considering as part of the diagnosis so it's not a shock if it does come along... So you say this and this are the possible diagnoses that you may have, and that is why we are doing these tests, and you should be aware that that [cancer] might be a possibility.*

### **Engage in patient-centred communication.**

HCPs emphasised building a relationship with Zulu patients by spending time with each individual patient and family, offering support and demonstrating personal interest.

*...some of them cry, we give that support and we give them the tissues and we let them cry out, so that at least we are there for them.*

HCPs also advocated assessing and addressing patient needs. Some emphasised observing what patient needs were and attending to these needs without patients having to ask. Others proposed assessing patient concerns from the beginning by asking patients about their concerns and fears, and then gauging their coping abilities regardless of whether they knew the diagnosis. Responding to patients' questions about the diagnosis was recommended.

*If the doctor has not yet told the patient about the diagnosis then we avoid discussing it but we look at what the patient's concerns are, what do they think is wrong, what are they afraid of...*

HCPs highlighted being sensitive to patients' varied reactions to the diagnosis. Proposed strategies for managing patients' denial included acknowledging that the diagnosis is difficult to accept, reinforcing the diagnosis and helping patients to accept the diagnosis.

*If the diagnosis has been made and the patient has been informed but still says I didn't know, no one told me, then we do reinforce that information because denial is evident in most of our patients...*

### **Engage in culture-centred communication.**

HCPs advocated taking responsibility for improving communication as patient-provider encounters at the study site are largely language discordant. One proposed strategy involved including some basic isiZulu phrases in conversations.

HCPs proposed demonstrating an understanding of Zulu cultural health beliefs by reassuring patients that their diagnosis was neither due to anything that they had done, nor punishment or bewitchment (common explanatory models among Zulu patients). They encouraged expressing a genuine interest in patients' culture by enquiring about their cultural and religious practices, their understanding of the aetiology of the condition, how they wanted to manage the condition, and their health beliefs. HCPs championed offering patients the best care possible regardless of language discordance.

*...we always ask what religion are they, what are the traditions that they practice.*

*If it is a cancer diagnosis I am going to ask, "where do you think the cancer came from, were you bewitched?" And sometimes the patients will laugh because they thought that but they didn't realise that I would have known. So they didn't want to mention it on their own and then they will tell the story of who they think bewitched them and what they did...*

### **Facilitate understanding of the diagnosis using visual aids.**

HCPs highlighted the importance of explaining the meaning of cancer to patients. The use of images was recommended, as patients can easily recognize on plain radiographs that bone with osteosarcoma is different from the normal bone and distinguish a healthy limb from a diseased one.

*...they see the x-ray, it looks odd, it's different from the normal size, they can see there's something.*

HCPs also recommended the use of pictures and giving patients the unit's osteosarcoma brochure.

**Facilitate understanding of the diagnosis using the stages of cancer.**

HCPs suggested using the stages of cancer to educate patients regarding their stage of the disease and the effects of cancer in every stage, including the occurrence of metastases.

*When I discuss diagnosis I always discuss stages. From the very beginning the patients will know which stage they are in and as that changes ideally we should explain to the patient that there is mets (metastases) here...*

**Facilitate understanding of the diagnosis using metaphors.**

HCPs proposed the use of metaphors to explain concepts like cells, organs, tumours and metastases and indicated that patients seemed to understand the "house" metaphor best.

*So I often use a house... building blocks of a house, each block is a cell and they group together in a certain way to form a different part of the house. And each part then has a different function and I think it is more tangible so patients can understand that. So the tumour then is a lump which grows so that part of the wall of the house for example is not strong enough to do its job. For metastasis then we say some of those blocks have broken off, they float to other parts of the house and now they are making a lump there.*

Participants indicated that patients may also use metaphors to demonstrate their own understanding of their illness and suggested that HCPs use these patient-initiated metaphors when discussing their condition.

### **Checking for patient understanding.**

HCPs highlighted repeating information and checking patient understanding and emphasised checking what patients remembered from previous explanations.

*What I do find is that all of that information does not generally get absorbed, so you generally have to repeat.*

*...at the next interview check how much they remember and understand...*

### **Address language barriers.**

HCPs recommended using language that patients understand, avoiding medical jargon and using interpreters who share the information correctly. They advocated using professional interpreters.

*...I think we need to maybe try harder and improve communication. I think that is really important... we mostly all English speakers here but majority of our patients are Zulu, mother tongue Zulu speakers.*

### **Instil hope through MDT involvement.**

HCPs reported that patients inevitably feel abandoned at some point; they therefore reassured patients of the continued involvement of the MDT, regardless of diagnosis and outcome.

They explained the role of all team members coupled with a differentiation of the various aspects of care and how they would be addressed. Maintaining hope was advocated regardless of disease stage.

*...this is just one sphere of your management here, you are still going to be seen by an oncology team, there is a psychologist, there is a social worker that's going to help you, you are not going to be left alone at this time... we are going to help you in different areas of your life...*

### **Complicating factors in communicating with Zulu patients**

Patient, healthcare professional and organisational factors that complicate communicating the diagnosis of osteosarcoma to Zulu patients are displayed in Table 3.

Table 3: Complicating factors in communicating with Zulu patients

<b>Subthemes</b>	<b>Factors that complicate breaking bad news</b>
Patient factors	<p>Cultural health beliefs</p> <ul style="list-style-type: none"> <li>cancer diagnosis is viewed as a punishment</li> <li>cancer diagnosis may be attributed to being bewitched</li> <li>cancer diagnosis is associated with a poor prognosis</li> </ul> <p>Zulu word for cancer is associated with poor prognosis</p> <p>Lack of clarity regarding how much patients understand about the diagnosis</p> <p>Patients understand consequences of the diagnosis and not the actual diagnosis</p> <p>Lack of clarity regarding words in Zulu for the diagnosis of osteosarcoma</p>
Healthcare provider factors	<p>Lack of training</p> <p>Perceived lack of competence</p> <p>Tendency to use medical jargon</p>
Organisational factors	<p>Disjointed MDT functioning</p> <ul style="list-style-type: none"> <li>unclear documentation in the medical file</li> <li>delays in patient needs being addressed</li> </ul> <p>Resource constraints</p> <ul style="list-style-type: none"> <li>attendance and scheduling of MDT forums</li> <li>lack of access to professional translators</li> <li>nursing time constraints</li> </ul>

### **Patient factors.**

HCPs reported that Zulu patients generally viewed a cancer diagnosis as an ancestral punishment or believed that they were being bewitched. Culturally, a cancer diagnosis was associated with a poor prognosis, often due to Zulu patients being socialised to believe that cancer kills.

*Zulu patients, most of the time they'll say they have been bewitched.*

Participants reported that the isiZulu word for cancer is *umdlavuza*, meaning 'something that ravages, something that destroys everything, something that cannot be stopped'. For Zulu patients *umdlavuza* is cancer, and it cannot be mistaken for another illness. HCPs viewed the term as problematic for cancers that can be cured.

HCPs were concerned about how well patients actually understood their diagnosis. Patients seemed to understand the treatment of the diagnosis better than they understood the diagnosis. The lack of words in Zulu for osteosarcoma posed another challenge.

*And I think patients understand more the consequences of the diagnosis than the diagnosis itself. With this diagnosis I am going to cut off your hand, with this diagnosis I am going to have to give you so much of medication...*

### **Healthcare professional factors.**

HCPs reported a lack of training and a perceived lack of competency with regard to communicating the diagnosis of cancer. Most indicated that they had learnt how to break bad news only by observing others. The orthopaedic surgeons and registrars were concerned that

they have a tendency to communicate too directly and be too task-oriented. Participants could not agree on whether there was one preferred method for discussing diagnosis; they were also unsure as to whether the diagnosis was thoroughly explained to patients. They expressed a need for practical instructions.

*...I don't know if I am doing it correctly... because I don't know if I am doing it right and the thing is the way I do it is kind of like I saw other people do it in what I think might be right...*

HCPs reported the use of medical jargon thus detracting from the culture-centred communication previously advocated.

*...the manner in which the information is communicated to the patient is sometimes done in medical jargon. So you have a tumour that has metastasized, means nothing to people English or Zulu speaking who don't have a medical background.*

### **Organisational factors.**

HCPs reported challenges with MDT functioning arising from disjointed communication between team members. Documentation in the medical file did not report on whether patients had been informed of their diagnosis and what their level of understanding was making it difficult for allied health professionals to know what they could say to patients. Patients also had to wait for queries to be addressed as they would enquire about something from the wrong team member who then had to relay the message to the appropriate team member.

*I have seen before where like the psychologist will go to see the patient and I will see the notes from the psychologist saying patient is asking about prosthesis, please educate patient on this or patient is asking about how much weight they will lose and what they can eat please ask the dietician... we kind of segmented... compartmentalized in what we do... So also the patient is getting sent from one person to the next with each person discussing their thing in a different time. He wants to know about a prosthesis now, that is his biggest concern and maybe a day or two later he can only get answers for that.*

Organisational resource constraints posed another challenge. All members of the MDT could not attend the TSR ward rounds and the Osteosarcoma MDT meetings had not been scheduled due to resource constraints.

*We do have meetings; we have the osteosarcoma meetings, team meetings. And it was active for at least, well I think maybe four or maybe two or three months we haven't... We haven't had a meeting this year ...*

Lack of access to professional interpreters was another resource constraint. HCPs often did not have access to the interpreter before speaking to the patient. They were also concerned that they were placing the onus on the interpreter to inform patients of a cancer diagnosis. Inexperienced interpreters and patients were perceived to downplay the core message, and HCPs questioned the accuracy of their interpretations. They were concerned that student nurses lacked competence due to possible lack of knowledge about the condition and discomfort with breaking bad news. A reluctance to use metaphors, especially when the interpreter was inexperienced was reported.

*...they send the student nurse who has just come out of gynae or something. She has got no idea about cancer yet because she has just started. And you know she has got to explain this now and it is difficult and even when I listen... I mean I am not Zulu I can hear sometimes there is things that is being said or being downplayed or you know things that are changed in translation.*

Nurses reported on time constraints with regard to not having enough time to spend with patients after the diagnosis had been disclosed despite realising that they needed time to process the information.

*...you're so pressed for time you've got all these other patients to attend to...*

## **Discussion**

Our results confirm the use of several strategies reported in the literature, including: the practice of preparing patients early for the possibility of a diagnosis of cancer (Girgis & Sanson-Fisher, 2010; Lind, DelVecchio Good, Seidel, Csordas, & Good, 1989); assessing patients' knowledge and understanding of their condition (Girgis & Sanson-Fisher, 2010; Lind et al., 1989; Maguire, 1998; Narayanan, Bista, & Koshy, 2010; Travaline, Ruchinkas, & D'Alonzo, 2005); providing information in increments to reduce shock (Girgis & Sanson-Fisher, 2010; Maynard, 1996; Numico, Anfossi, & Bertelli, 2009); informing patients of the reason for diagnostic tests as a means of preparing them for the diagnosis (Girgis & Sanson-Fisher, 2010); and warning patients on several occasions regarding the possibility of a cancer diagnosis (Girgis & Sanson-Fisher, 2010; Lind et al., 1989; Maynard, 1996; Travaline et al., 2005). This kind of patient-centred approach (Barclay, Blackhall, & Tulsy, 2007; Epstein &

Street, 2007; Moore et al., 2012; Schmid Mast, Kindlimann, Langewitz, 2005) also comprises relationship building (Epstein & Street, 2007; Platt & Keating, 2007); identifying patient needs and concerns (Maguire, 1998; Monden, Gentry, & Cox, 2016); using open-ended questions to elicit patient concerns (Barclay et al., 2007); answering patients' questions openly and honestly (Randall & Wearn, 2005); addressing patients' emotional responses by offering support, and validating patients' responses and reinforcing the diagnosis (Baile et al., 2000; Brock, Gurekas, & Deom, 1993; Epstein & Street, 2007; Maguire, 1998). Delivering culturally and linguistically sensitive services (Dein, 2004) necessitated taking responsibility for improving communication by providing information in the patient's language or developing a vocabulary of terms that is familiar to patients (Mullin, Cooper, & Eremenco, 1998) and engaging in a dialogue with patients to explore cultural issues (Barclay et al., 2007; Epner & Baile, 2012). Strategies for facilitating patient understanding entailed using images, pictures and information booklets (Doak et al., 1998; Randall & Wearn, 2005; Shahid, Durey, Bessarab, & Aoun, 2013); using metaphors (Arroliga, Newman, Longworth, & Stoller, 2002; Casarett et al., 2010); and listening for patients' imagery and metaphors of their illness experience as a means of finding a common language for connecting with patients (Harrington, 2012; Reisfeld & Wilson, 2004). Repeating information, checking patient understanding (Baile et al., 2000; Epstein & Street, 2007), using simple language, avoiding medical jargon (Epstein & Street, 2007; Girgis & Sanson-Fisher, 2010; Shahid et al., 2013; Chatuverdi, Strohschein, Saraf, & Loiselle, 2014), and using experienced and professional interpreters (Barclay et al., 2007; Epner & Baile, 2012; Kagawa-Singer et al., 2010; Ngo-Metzger et al., 2006; Shahid et al., 2013) are also documented strategies. The therapeutic value of communicating hope at all stages of the disease (Barclay et al., 2007; Travaline et al., 2005) is denoted in the literature.

Particular to this study, HCPs proposed several unique strategies for communicating in cross-cultural clinical settings. First, the strategy of culture-centred communication was extended beyond merely exploring cultural issues with patients to actively introducing cultural narratives in order to demonstrate knowledge of and openness to patients' cultural practices and beliefs. Second, a new strategy for facilitating patient understanding involved explaining the stages of cancer to patients by informing them of their stage and of how cancer affects the body in every stage. This stage approach was also advocated as helpful for discussing metastases. Third, although commonly documented metaphors in the discourse of cancer include the war metaphor and the journey metaphor (Reisfeld & Wilson, 2004), HCPs in this study proposed the use of a 'house metaphor' and reported that patients responded well to this analogy. The use of metaphor in this cross-cultural clinical setting is reported to be useful hence HCPs in other cross-cultural settings should be encouraged to discover metaphors that may work in that specific context. Fifth, HCPs recommended checking what patients remembered and understood from previous explanations given. This strategy allowed HCPs to check for misperceptions and denial. Last, HCPs suggested instilling a relational hope that was not necessarily associated with cure but reassured patients of the MDT's continued involvement throughout the disease process. HCPs used this strategy to ensure that patients did not feel abandoned thereby reinforcing the premise that hope is not exclusively dependent on cure (Back et al., 2008).

Our results also highlighted factors that complicate communicating a diagnosis of cancer to Zulu patients. Zulu patients' fatalistic view of cancer and perception of cancer as a punishment have been reflected in studies of other cultural groups (Austin, Ahmad, McNally, & Stewart, 2002; Gullatte, Brawley, Kinney, Powe, & Mooney, 2010; Lasser, Ayanian, Fletcher, & DelVecchio Good, 2008; Lourens, 2013; Pérez-Stable, Sabogal, Otero-Sabogal, Hiatt, & McPhee, 1992), and such fatalistic views can seriously hamper help-seeking

behaviours (Austin et al., 2002; Lasser et al., 2008; Lourens, 2013). HCPs concern in this study about how much patients actually understand about their diagnosis is reflected in other research (Richardson, Thomas, & Richardson, 2006). Healthcare professional factors included lack of training (Barclay et al., 2007; Barnett, Fisher, Cooke, James, & Dale, 2007; Hebert, Butera, Castillo, & Mega, 2009; Monden et al., 2016; Payán et al., 2009), a perceived lack of competence (Girgis, Sanson-Fisher, & McCarthy, 1997) and learning the skills required by observing others (Colletti, Gruppen, Barclay, & Stern, 2001). The reported use of medical jargon was another challenge (Chapman, Abraham, Jenkins, & Fallowfield, 2003), as choice of vocabulary affects patient satisfaction and using the same vocabulary as the patient can improve patient outcomes (Williams & Ogden, 2004). Organisational factors impeding communication included lack of clear documentation as to previous patient communication which has been reported as a barrier to co-ordination of patient management and clinical governance (Barnett, Fisher, Wild, & Dale, 2002). Other organisational challenges pertaining to delays in patient queries being addressed, attendance and continuity of MDT meetings, lack of access to professional interpreters, and nursing time constraints may be attributed to financial and healthcare staffing constraints (Harrison, 2009) which have been documented as challenges with regard to continuity of cancer care (Lauria, 1991). The MDT literature advocates regular meetings for improved MDT communication (Fay, Borrill, Amir, Haward, & West, 2006; Fleissig, Jenkins, Catt, & Fallowfield, 2006) and cautions against MDT members working independently and liaising with one another informally (Miller, Freeman, & Ross, 2001). HCPs concerns regarding working with inexperienced interpreters (Richardson et al., 2006) and not having access to interpreters prior to communicating with patients (Barclay et al., 2007; Epner & Baile, 2012) is reflected in other cross-cultural research. Nursing time constraints pose another challenge as patients tend to value the

beneficial support of nursing staff and relied on them to supplement and clarify information (Warnock, Tod, Foster, & Soreny, 2010).

HCPs in this study highlighted distinctive factors that complicate communicating the diagnosis of cancer to Zulu patients. Zulu cultural health beliefs highlighted the divide between Western and traditional systems of health and illness. The Zulu people generally view the cancer diagnosis as an ancestral punishment or resulting from witchcraft and have been socialised to associate a cancer diagnosis with a poor prognosis. The isiZulu word for cancer reflects these cultural health beliefs and presents a significant barrier as the meanings associated with this word significantly complicates the diagnosis discussion especially when a good prognosis is possible. Language barriers present a significant challenge in this cross-cultural setting. The lack of availability of medical terms in Zulu and the limitations with regard to the translatability of words into the patient's language significantly impacts patient understanding. Language barriers further manifest in the lack of access to professional interpreters. Although the use of metaphor has been reported to be effective with Zulu patients and in oncology settings in general (Arroliga et al., 2002; Casarett et al., 2010; Reisfeld & Wilson, 2004), HCPs reported a reluctance to use metaphors, particularly when the interpreter was inexperienced, and thus hindering an opportunities for patients to have a greater understanding of their diagnosis.

### **Limitations**

All those approached to participate were not available at the time of data collection, and this may have limited our ability to achieve data saturation. Although our use of discipline specific focus groups likely enhanced our ability to explore issues common to each professional group, it also may have restricted our opportunity to assess the inter-professional functioning of MDT members, which is likely an important factor given the high pressure

environment in which the study was conducted. Our results may have been enhanced had other qualitative data gathering techniques been used to complement the focus group interviews.

### **Conclusion**

This study exposed distinctive strategies for communicating the diagnosis of cancer with Zulu patients in South Africa. These strategies include actively introducing cultural narratives in order to demonstrate knowledge of and openness to patients' cultural practices and beliefs, using the stages of cancer to explain the disease and its progression, effective use of metaphor to facilitate patient understanding, checking patients' memory of previous discussions as a means of identifying misperceptions, and instilling hope through continued MDT involvement regardless of disease stage. We believe these strategies are likely valid in other cross-cultural clinical settings.

As well, several distinctive challenges emerged from this study. They pertained to patients' cultural health beliefs and the issue of patient understanding and lack of vocabulary for various medical conditions in indigenous languages. Language barriers had far-reaching consequences for facilitating patient understanding as a lack of access to professional interpreters left HCPs unsure of what was being communicated and hesitant to use metaphors in their communication with patients.

This study produced unique strategies which will make a contribution to MDTs working with indigenous populations. It is therefore important to conduct research of this nature in other cross-cultural clinical settings. Our findings also emphasised the vital importance of training HCPs on communication of sensitive information in cross-cultural clinical settings. Most research and protocols for breaking bad news are generic; few refer to considerations that are specific for the particular cross-cultural clinical setting. While directions from these protocols are useful research resulting in recommendations for

managing the unique challenges encountered in any particular cross-cultural clinical settings is much needed. This study will contribute to the development of such recommendations for communicating the diagnosis of cancer across various cross-cultural boundaries.

### **Acknowledgments**

We acknowledge the participants, Dr Wilma ten Ham-Baloyi and Mr Kegan Topper for reviewing the qualitative data, and Prof William Ventres for commenting on this manuscript.

### **Declaration of Conflicting Interests**

The Authors declare that there is no conflict of interest.

### **Funding**

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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**Chapter 4: Communicating about Treatment of Osteosarcoma in Cross-Cultural Clinical Settings: A Qualitative Review of Content, Process, Challenges, and Strategies**

Brown O., Goliath V., Aldous C., Van Rooyen D., Marais L

**Submitted to the European Journal of Oncology Nursing**

## **Communicating about treatment of osteosarcoma in cross-cultural clinical settings: A qualitative review of content, process, challenges, and strategies**

### **Abstract**

An extensive literature exists on how to break bad news with regard to diagnosis and prognosis. However, research regarding the discussion of treatment options across cultural boundaries is sparse. This article reports on the manner in which treatment of osteosarcoma is discussed in a cross-cultural context with Zulu patients in South Africa. Methodologically, we conducted focus group interviews with professional nurses, allied health professionals, and orthopaedic physicians. Three focus groups with a total of twenty-three participants were conducted. We thematically analysed the interview transcripts using Guba's Model of Trustworthiness to ensure rigour. We found that factors influencing treatment discussions in this cross-cultural clinical setting included the meaning and disclosure of cultural health beliefs. We identified strategies for responding to cultural factors associated with amputation, namely timing treatment discussions, and using support services, patient models and DVDs/videos. Strategies for responding to cultural and health beliefs that affect treatment included initiating the cultural discussion, demonstrating an understanding of patients' cultural beliefs and, liaising with family and cultural decision-makers where possible. Our findings emphasised healthcare professionals' reports of how patients can experience the discussion of culturally discordant treatment options as bad news. We recommend that the treatment discussion forms an integral part of guidelines for culturally competent communication with cancer patients.

**Keywords:** cross-cultural communication; treatment; cancer; osteosarcoma; cultural competence

## **Introduction**

An extensive literature exists on communicating the diagnosis and prognosis of cancer to patients (Bennett and Alison, 1996; Figg et al., 2010; Girgis and Sanson-Fisher, 2010; Hagerty et al., 2005; Monden et al., 2016). However, the literature on discussing treatment options tends to be limited (Baile et al., 2000; Girgis and Sanson-Fisher, 2010). Research regarding the discussion of treatment options across cultural boundaries is especially sparse. Although informing patients of their treatment options and ensuring that they understand these options is considered good practice (Girgis and Sanson-Fisher, 2010), patients tend to be less satisfied with discussions regarding treatments as compared to those in which diagnosis is communicated (Galletari et al., 2002). In this study we explored healthcare professionals' (HCPs) accounts of how treatment options are discussed in a cross-cultural clinical setting. It was conducted in the province of KwaZulu-Natal (KZN), South Africa, where healthcare encounters are largely culturally discordant, and focused on Zulu patients diagnosed with osteosarcoma.

Previous research at our study site reported that the majority of patients present with locally advanced or metastatic disease (Ferreira and Marais, 2012), which limits treatment options and results in very poor prognosis (Errani et al., 2011; Ferreira and Marais, 2012; Marais et al., 2015; Meazza and Scanagatta, 2016; Ritter and Bielack, 2010). With regard to surgical treatment options, a significant shift away from amputation to limb salvage (around 80% of patients) has been reported (Bielack et al., 2009; Jaffe 2009). However, a substantial proportion of patients presenting at the study site are not candidates for limb salvage due to the advanced stage of the disease at presentation (Ferreira and Marais, 2012). HCPs consequently have to simultaneously inform patients of the diagnosis of osteosarcoma as well as the significant limitations with regard to treatment options. The purpose of this research study, therefore, was to understand how treatment is discussed in this context with the intention of identifying cultural factors associated with discussing treatment options.

## **Research Methodology**

### ***Study Setting***

The study site offers uniqueness as it is the only facility in Western KZN that treats osteosarcoma and that offers patients a multidisciplinary (MDT) approach to management. The MDT comprises orthopaedic consultants and registrars; nurses from the orthopaedic and oncology outpatient clinics and wards; and allied health professionals including dietitians, occupational therapists, physiotherapists, social workers, and clinical psychologists. The

majority of the patients treated at this hospital belong to the indigenous Zulu ethnic group and isiZulu (one of South Africa's 11 official languages) is their native tongue. HCPs receive medical training mostly in English or at some universities in Afrikaans and the majority of healthcare professionals are not of Zulu origin (Table 1). Zulu patients also typically engage in cultural health beliefs and practices that are in contrast to the Western medical model within which medical training is housed. They may conceptualise illness as resulting from displeasing the ancestors, witchcraft or troublesome social relationships (Vorobiof et al., 2001; Mdongolo et al., 2003).

### ***Research Design and Methods***

We used a qualitative exploratory descriptive and contextual approach and conducted focus group interviews with three distinctive groups of professionals: professional nurses; allied health professionals; and orthopaedic physicians (including consultants and registrars). The focus group interview schedule was piloted with a social work colleague who has experience with working with cancer patients in the study setting. Interview questions focused on approaches that HCPs take when discussing the treatment of osteosarcoma with Zulu patients and the cultural considerations pertaining to this discussion.

### ***Participants and Sampling***

We recruited participants using census sampling. All 23 study participants were members of the multidisciplinary team involved with the care of Zulu patients with osteosarcoma. Five team members could not participate due to scheduling conflicts. Only four of the participants were isiZulu speaking highlighting the culturally discordant medical encounters at this health facility. For purposes of describing the sample and contextualising the findings, the demographic details of the sample are outlined in Table 1.

Table1: Focus group demographic information (n=23)

Orthopaedic consultants and registrars	n=9
Registered nurses from orthopaedic wards, orthopaedic clinic, oncology clinic and pain service	n=5
Allied health professionals (physiotherapists, occupational therapists, dieticians, social worker)	n=9
Gender	
Males	n=8
Females	n=15
Ethnic Group (South Africa)	
White	n=13
Indian	n=4
African (Zulu)	n=4
Coloured	n=2

***Data Collection, Analysis and Trustworthiness***

The second author, an experienced qualitative interviewer, conducted the focus groups as she had no prior knowledge of the participants. The focus group interviews were conducted at the hospital as the participants work in a resource constrained environment and ranged in duration from 54 to 95 minutes. Interviews were audiotaped, transcribed verbatim and analysed for themes (Braun, 2006). The data was independently coded by the focus group interviewer and the primary investigator and further reviewed by two qualitative research experts before consensus was reached on the themes. Guba’s Model of Trustworthiness (Lincoln and Guba, 1985) was used to ensure rigour.

***Ethical Approval***

Ethical clearance to conduct the study was obtained from the Biomedical Research Ethics Committee at the University of KwaZulu-Natal. Anonymity was enhanced as the focus group interviewer had no prior contact with the participants. Voluntary participation and informed consent applied.

## **Results**

Three themes emerged from our focus group interviews. The first theme reports on the communication with Zulu patients about treatment options. The second theme highlights the cultural factors associated with the treatment discussion, and the last theme focuses on strategies used to respond to these factors. Importantly, the focus group process was transformative (De Laine, 2000) as it allowed for the Zulu HCPs to educate other participants about Zulu cultural beliefs and practices which enhanced awareness of cultural factors to be taken into account when communicating with Zulu patients.

### ***Communicating with Zulu patients about treatment***

This theme outlines the content, process and emotional aspects of the treatment discussion.

#### ***Communicating about treatment options***

HCPs reported that the type of surgical procedure (limb salvage surgery or amputation) depended on whether (1) the tumour could be excised with wide margins and (2) a functional reconstruction of the limb could be achieved. If limb salvage surgery was a possibility, the orthopaedic physician explained to the patient that the cancer would be excised and replaced with a prosthesis. Participants also informed patients that chemotherapy was needed to shrink the tumour so that it was safer to excise it and salvage the limb. HCPs showed patients a joint replacement, explaining that limb salvage was like a knee replacement on a larger scale.

If patients required amputation, HCPs reported informing them that this was the only option. They informed patients without metastases that amputation would be potentially curative. They advised patients with lung metastases that metastasectomies could be performed.

Participants reported explaining to patients with borderline tumours (when HCPs are uncertain whether limb salvage or amputation will be performed) that they would first administer chemotherapy to shrink the tumour and would only subsequently make decisions about limb salvage or amputation. They perceived that patients tended to understand the explanation of chemotherapy shrinking the tumour. If amputation was the only option following chemotherapy, HCPs informed patients that if the tumour was removed and limb salvage was attempted, the limb would not be functional following tumour resection. They described explaining the latter in terms of lack of blood flow to the limb and neurological impairment.

*I say look there is no way for us to take the tumour out and the leg to remain you will have no blood flow to the leg or no feeling in the leg... we have to do an amputation.*

#### *The process of discussing treatment with the Zulu patient*

HCPs proposed that patients should be told at the initial visit that treatment would be discussed in greater detail once the diagnosis was confirmed. They reported that this was difficult to achieve as patients requested treatment information immediately following diagnosis. Participants opted to discuss treatment options after informing patients of the prognostic consequences of not treating the tumour. Participants indicated that life-saving treatment discussions should be reserved for after the results of local and systemic staging investigations were available. They stressed that patients should be informed promptly, and emphasized noting that surgery is only one management possibility. Participants described how patients tended to only hear certain parts of the discussion at a time; they recommended repeating treatment options several times.

*The patient usually wants to know immediately. They say okay fine, I have got cancer but what are you going to do about it?*

Participants suggested that the stages of cancer be used to communicate with patients about the unpredictability of disease progression. As the disease progressed, this change in stage could be used to explain adjustments in treatment goals. Patients should be informed of what is realistically possible in terms of treatment given the stage of the disease.

*So you give them the options and say listen, if we have got all the staging... this is what we need to do as a best shot to try and save your life.*

Orthopaedic physicians indicated that they were careful about the language used in order to balance hope with honesty. They avoided using the word “save”, preferring instead the “best chance to save”. They told patients there were no guarantees, so as not to create false hope.

#### *Patient and provider emotions regarding the treatment discussion*

Participants were concerned patients would react negatively if a patient-provider relationship had not been established prior to discussing drastic treatment options. Patients typically broke down when amputation was mentioned: they were very sad, tended to withdraw and sometimes refused hospital treatment. After discussing treatment options, especially amputation, patients usually wanted to return home to consult with elders, family members, and/or traditional healers. Often they did not return, delayed returning (which worsened prognostic outcomes), or, upon returning, refused further treatment.

*...they know they are going to have an amputation, they are very sad. I had a patient who, I just went to greet him and he sobbed. He pulled his blanket over his head and cried like a baby.*

*...as soon as you say well the treatment that would help you the most is an amputation... that's then when everything becomes a problem. That's when the whole communication breaks down, as soon as you say amputation, they shut down completely and they don't listen any further from there...*

Participants found that patients typically responded well to the option of limb salvage.

*...people normally don't worry too much about that, if they hear... that they can keep their leg... they normally relax and they are not worried...*

HCPs reiterated that they experienced a sense of urgency during the treatment discussion. They felt pressured to act before the disease spread, especially in non-metastatic cases. They were concerned about being direct with patients regarding the implications of not treating the condition, but insisted that truth-telling was the best approach. Orthopaedic physicians that were not Zulu felt disadvantaged as they perceived that traditional healers are able to claim cure while they are ethically and legally mandated to ensure that patients are well-informed.

*So we have got this pressure on us and we need to get this thing out, it's going to spread...*

*You can understand why we had such a massive disadvantage compared to a traditional healer. They are not bound by medico-legal, I can sue you type of ethics. (They say) I will cure you and everybody has a big party... Because you are ethically bound and legally bound to tell the patient everything to take informed consent, you tell them it can kill you, it may very well kill you. If we don't do anything it will kill you, if I operate on you, you can die on the table. If we do everything and it goes perfectly it might come back later and kill you. We just end up saying all these horrible things.*

### ***Cultural factors influencing the treatment of osteosarcoma***

Participants reported that culture plays a significant role in the discussion of treatment.

#### *Zulu cultural and health beliefs*

HCPs indicated that some patients were concerned about community exclusion post amputation. They also reported that Zulu patients' cultural beliefs dictate that they cannot become an ancestor if they have an amputation because their body would be incomplete. Participants suggested that these cultural beliefs were changing, as more patients were consenting to amputation. They attributed this change in belief to education initiatives on the radio.

*...that's part of the belief... once you have an amputation then you don't really belong to that community... they don't really accept you that well...*

*...and he died from it in the end, from a giant cell tumour... he said if you amputate me I won't become an ancestor, so I am refusing...*

*Is that changing? Because we are getting more consent for amputations...*

*It is changing, there is a lot of discussions that are actually going on about that...*

*Radio works well, they speak about these things (cultural beliefs).*

Participants indicated that patients and/or their elders wanted to engage in traditional healing in an attempt to achieve cure and prevent amputation. Traditional healers can claim cure, which results in the community rejoicing. Patients preferred to go home as opposed to complying with HCPs' proposal to invite family members to the hospital. Participants were

concerned that patients would neglect Western medicine when traditional options were seen by patients as mandatory.

*...they will tell you I want to go and see a traditional healer.*

*So the intention with going to consult a traditional healer is because you as a patient believe that there is cure...*

*...I do try and see if we can get any means to get to the family to come but most of the times they want to go back home rather than bringing someone.*

*So how about going back home... they (the elders) will point out there is a good traditional healer that might help... but now they forget about the Western part of medicine.*

Zulu HCPs discussed the cultural hierarchies in Zulu families and the significance of these hierarchies in decision-making. Participants reported that patients need to consult with their elders before agreeing to treatment even when they understood the nature of the condition.

*...we have hierarchies at home, from my father, to go down to my uncles and everybody... And then the issue will be discussed with all of them and then they will come up with their own inputs...*

HCPs were concerned that the cultural decision-maker might not have insight into the patient's condition and that patients would be deserted by the cultural hierarchy if they ignored their advice and made decisions independently.

*If you disregard or ignore her decisions, she (an identified elder) will decide to pull out and you feel that you are on your own... If let's say you have made a bad decision, she will say, but I told you and you went on and you got it wrong and you listened to those people, now you are on your own...*

### *Patient disclosure of traditional beliefs to providers*

HCPs perceived that patients' willingness to share their cultural beliefs is an individual preference. Some patients withheld their desire to consult a traditional healer; others admitted to this need. There was no consensus regarding patients' disclosure preferences. Some patients disclosed their traditional beliefs with greater ease to Zulu healthcare professionals whereas others more easily disclosed these beliefs to non-Zulu caretakers when prompted.

*You find that there's a sister at our front desk, let's say it's a white sister or an Indian sister, she will prefer to come to me maybe because of the language barrier. (Zulu nurse participant)*

*Most of the time if you actually speak to them (Zulu patients), (and ask them) are you going to go and see someone (traditional healer), they will tell you, well actually... you see...*

Conversely, participants observed a link between patients' reluctance, fear or embarrassment to disclose cultural beliefs and their perception that Western medicine is against cultural beliefs. Patients may therefore perceive that HCPs would try to hinder their compliance with cultural expectations.

*I think they are scared to tell us because they think we believe that it's you know...*

*And that we are going to try and stop them.*

*Especially that they know that at the hospital there's that thing of medical, you know, against cultural...*

### ***Responding to cultural factors associated with the treatment discussion***

Strategies for responding to the cultural factors associated with amputation and patients' cultural and health beliefs emerged from the data.

#### *Strategies for responding to cultural factors associated with amputation*

Timing the treatment discussion was viewed as a means of preventing the patient from signing refusal of hospital treatment (RHT) before diagnostic testing was complete. HCPs

emphasized the importance of not answering questions regarding treatment options for osteosarcoma before the diagnosis was confirmed.

*I generally then stop and say well let's not talk about that now, let's focus on finding out what it is first and then once we know we will talk about what the possibilities are for treatment after that.*

Another proposed strategy involved introducing patients to veteran patients. Participants suggested accessing patients who have been through the process successfully as models; including a patient model in the MDT to inspire newly diagnosed patients; and making a video of patients with successful outcomes. Exposure to veteran patients could result in ongoing support and demonstrate survival and the efficacy of Western medicine. However, patient models could demise and this should be considered when making these introductions. Using known characters/celebrities with access to better resources could create false expectations and should be avoided.

*Like somebody who has gone through it (Zulu patient with amputation) and they can say look I am out of it on the other side, this has actually helped me.*

Participants tended to respond to refusal of amputation by: (1) offering patients other treatment options like chemotherapy; (2) facilitating follow up with oncology and other services like psychology, social work and dietetics, and (3) mobilising support by including the psychologist in diagnosis and treatment discussions where possible.

*...because if we get a diagnosis and he then refuses amputation but is willing to stay we can still do... chemo and (facilitate follow up from) dietitians and psychologists... oncology.*

#### *Strategies for responding to cultural and health beliefs that affect treatment*

Participants reported needing to balance cultural sensitivity with the urgency for prompt treatment. HCPs accepted their onus to initiate discussions about cultural requirements in order to fast track decision-making.

*...ask this patient what is important to them and how do they see themselves managing this, do they feel they need to go to the Sangoma (traditional healer). I think time is also wasted because we expect the patient to tell us their needs like... I want to go home to discuss this...whereas if we initiated it and said what do you want to do now, what does your family think needs to happen we would maybe know on day one or day two...*

HCPs' emphasized the importance of acknowledging patients' need to discuss treatment with their family and encouraging patients to engage in their cultural traditions. They suggested that patient guilt regarding choosing Western medicine could be mediated by encouraging cultural rituals. Participants also reported encouraging patients to follow Western and traditional approaches to managing health and illness.

*...I do understand that you, you want to discuss with the family...*

*...you don't want them to feel guilty about not following the culture but following the Western medicine culture.*

Participants reported that they tried to liaise directly with family and cultural decision-makers where possible. This practice improved communication. Negotiation was frequently used to persuade patients to not go home; rather suggesting they invite family members to the hospital.

*...if they say they want to speak to their family, what I usually do (is ask the patient) can't you get someone to come so that we can explain to them and then that person can go and explain to the family what is happening...*

HCPs reported that when patients insisted on going home they gave the patient a deadline for returning from the family consultation and explained to the patient that the traditional healer would not be able to assist just as Western medicine could not cure every illness. They also reiterated with patients that the final decision was with them and not with the family. Participants ensured that patients were still well-informed.

*...I do explain to them that okay it is your decision, whatever treatment options that we are going to give you. It's your decision to make, it's not somebody else's decision at home...*

Participants proposed specific strategies for culturally competent communication. They reiterated not making assumptions based on culture and race, proposed taking responsibility for learning about the Zulu culture, and suggested including traditional healers in patient care.

*I think culture is very specific to an individual, we mustn't think that all black patients are going to have that same culture...*

*...the Department of Health as a government department needs to find a way to incorporate traditional healers into the medical setting.*

## **Discussion**

### ***Communicating with Zulu patients about treatment***

Healthcare professionals in this study highlighted how they approached the task of discussing the treatment options for osteosarcoma with Zulu patients. The facts that the HCPs presented to patients were consistent with factual accounts in the literature (Errani et al., 2011; Luetke et al., 2014; Murphey et al., 1997; Ritter and Bielack, 2010). The process aspects of treatment discussions centred on delaying treatment information until staging investigations were completed; being clear about the consequences of not treating the tumour; balancing hope and honesty; and ensuring patient understanding by using analogies, repeating information, and by using the stages of cancer to explain disease progression and realistic treatment options.

Previous works have emphasised the importance of executing treatment discussions in a manner that engenders patient cooperation (Baile et al., 2000; Girgis and Sanson-Fisher, 2010). HCPs in this study worked to engender such cooperation by acting promptly and encouraging patients to do the same in light of their late stage at presentation (Ferreira and Marais, 2012). Although it has been suggested that patients' readiness to hear treatment information should be assessed only after sharing the diagnosis and prognosis (Baile et al., 2000; Girgis and Sanson-Fisher, 2010), participants in our study reported skipping this step. HCPs were concerned about being overly direct with patients, but chose to be frank about poor prognostic outcomes in an attempt to communicate the seriousness of the condition.

This practice is in contrast to research that has indicated reluctance on the part of HCPs to reveal prognostic information (Fried et al., 2003; McGrath, 2002; Prigerson, 1992).

Emotional aspects of the treatment discussion pertained mostly to the treatment option of amputation. HCPs reported that amputation often evoked negative emotional and behavioural responses including an avoidance of treatment until the disease had progressed substantially. The latter demonstrates that cultural and health beliefs can negatively affect patients' health-seeking behaviours (Hodge et al., 2014; Merriam and Muhamad, 2013). In light of these emotional and behavioural responses, HCPs in our study appreciated the importance of the patient-provider relationship (Epstein and Street, 2007; Platt and Keating, 2007). They could also predict negative emotional responses to amputation which could facilitate appropriate management of patients' emotions; an essential component of the breaking bad news process (Baile et al., 2000; Girgis and Sanson-Fisher, 2010; Narayanan et al., 2010).

### ***Cultural factors influencing the treatment of osteosarcoma and their management***

HCPs in this study demonstrated considerable knowledge of Zulu cultural beliefs and practices, a characteristic deemed essential for working in cross-cultural clinical settings (Mullin et al., 1998; Pierce, 1997; Tucker, 2013). They emphasised taking responsibility for learning about the Zulu culture (Matthews-Juarez and Juarez, 2011; Muñoz-Antonia, 2014; Pesquera et al., 2008). Cultural aspects reported on included the belief of having to remain intact in order to become an ancestor after death; the fear of being excluded from the community post-amputation; the belief in traditional healing as a means of cure; and the role of the cultural hierarchy in decision-making. HCPs also reflected on patients' disclosure preferences and patients' hesitation to disclose their cultural beliefs given their perception that Western healthcare professionals may hinder their desire to observe their traditions (Davis et al., 2012; Robinson and McGrail, 2004; Shelley et al., 2009).

HCPs reported on patients' cultural beliefs regarding amputation. Proposed strategies for addressing Zulu patients' responses to amputation included timing the treatment discussion, and using patient models or videos of patients who have successfully rehabilitated after amputation as a means of easing patient anxieties and facilitating decision-making (Baile and Beale, 2001; Krouse, 2001; Schofield et al., 2008). Participants ensured that patients received care whether or not they chose amputation. If patients refused amputation, HCPs offered other treatment options, facilitated follow up from oncology and allied health

professionals, and mobilised support by including the psychologist in diagnosis and treatment discussions where possible (Baile and Beale, 2001; Girgis and Sanson-Fisher, 2010).

Participants reported on patients' belief in traditional healing. Strategies for responding to this cultural factor included encouraging patients to engage in their traditions, demonstrating respect for patients' preference to consult traditional healers, and proposing that patients combine traditional and Western medicine (Broome and Broome, 2007). Patients with traditional belief systems associate consulting a traditional healer with hoping for a cure and receiving spiritual and physical gain from the consultation (Muhamad et al., 2012). Participants were concerned about the paradigm divide of the hope of a miracle cure from traditional healers versus the Western medical message of no cure (Summerton, 2006). Research has shown that patients from indigenous populations, especially when diagnosed with a life-threatening illness such as cancer, may integrate Western medicine and traditional healing (Broome and Broome, 2007; Muhamad et al., 2012; Struthers and Eschiti, 2004). However, our study highlighted a concern that patients would neglect Western medicine when they returned home to engage in their traditions. HCPs also experienced that patients tended to delay returning to the hospital or avoided medical treatment completely.

Proposed strategies for fast-tracking treatment decision-making included initiating cultural discussions, liaising directly with the cultural decision-makers regarding treatment (Barclay et al., 2007; Broome and Broome, 2007), and suggesting that family members come to the hospital as opposed to patients going home. Most patients using alternatives to Western medicine may have an expectation of the clinician to initiate the discussion regarding these practices (Shelley et al., 2009). Furthermore, given the fact that the Zulu culture is located in a collectivistic paradigm where patients tend to defer to the collective for decision-making (Iwelunmor et al., 2014), liaising directly with cultural decision-makers may fast-track treatment. Despite HCPs' proposing that patients invite family members to come to the hospital, patients mostly insisted on returning home. Participants then tended to give patients a deadline for returning, warned them that traditional healing may not be effective, reminded patients that the ultimate decision was theirs, and ensured that patients were well-informed about their condition. These strategies denote a paternalistic, individualistic approach and demonstrate limitations with regard to veritable understanding of patients' cultural paradigms. Patients who have cultural health beliefs embedded in traditional healing believe in the curative capacity of traditional medicine (Muhamad et al., 2012). Similarly, reinforcing individualism with regard to decision-making negates the collectivistic paradigm within which Zulu patients operate (Washington, 2010). Although HCPs might be well-intentioned

and focused on life-saving, strategies used for patients that insist on going home are not indigenously collaborative and favour Western approaches to medical decision-making. HCPs in this study demonstrated a willingness to engage collaboratively cross-culturally. An awareness of the use of paternalistic strategies in response to patients that insist on going home will therefore assist HCPs to change this approach.

### ***Limitations of this Study***

Although themes were repeated within the focus groups, all members of the MDT were not available for data collection, and this may have limited our ability to achieve data saturation. Furthermore, our use of discipline specific focus groups may have restricted our opportunity to assess the inter-professional functioning of MDT members. We also note that the use of other qualitative data-gathering techniques may have complemented the focus groups and enhanced our data.

### **Conclusion**

This study, the first of its kind in the South African context, explored how treatment of osteosarcoma is discussed across specific cross-cultural boundaries, characterized cultural factors associated with discussing treatment options, and identified strategies for responding to these factors. Cultural factors highlighted included patients' beliefs about amputation, their need to access traditional healing and their requirements regarding collective treatment decision-making. Participants highlighted the importance of balancing respect for patients' cultural preferences with the need to expedite treatment decision-making in order to improve prognostic outcomes. Their proposed strategies for responding to patients' aversive responses to amputation entailed timing the treatment discussion, using patient models and visual media to ease patient anxieties, referring patients appropriately, and mobilizing support. Strategies for attending to cultural and health beliefs impacting on treatment decision-making included initiating the cultural discussion, seeking and demonstrating an understanding of patients' cultural beliefs, liaising directly with family and cultural decision-makers, learning about the patient's culture, and working collaboratively with traditional healers. While participants reported significant efforts to provide culturally competent care, medical paternalism emerged in response to patients that insisted on going home to engage in their traditions.

The strategies that we present will be useful in other cross-clinical settings where patients belong to collectivistic cultures and observe traditions and other practices that are significantly different to Western medical approaches. We recommend that guidelines for

culturally competent communication with cancer patients explicitly discuss the issues of managing culturally discordant treatment options. This study will contribute to the development of a guideline that will achieve this goal.

## **Acknowledgments**

We acknowledge the participants, Dr Wilma ten Ham-Baloyi and Mr Kegan Topper for reviewing the qualitative data, and Prof William Ventres for commenting on this manuscript.

## **Declaration of Conflicting Interests**

The Authors declare that there is no conflict of interest.

## **Funding**

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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**Chapter 5: Communicating about prognosis with regard to osteosarcoma  
in a South African cross-cultural clinical setting: Strategies and challenges**

Brown O., Goliath V., Aldous C., Van Rooyen D., Marais LC.

**To be submitted to Palliative and Supportive Care**

## **Communicating about prognosis with regard to osteosarcoma in a South African cross-cultural clinical setting: Strategies and challenges**

### **ABSTRACT**

*Objectives:* Effective prognostic communication with patients is a prerequisite for treatment decision-making, yet it is a difficult task to manage with confidence. This paper explored the strategies used and challenges faced when communicating about prognosis in a cross-cultural clinical setting.

*Methods:* We used a qualitative exploratory descriptive contextual design and gathered data using focus group interviews with healthcare professionals. Twenty-three healthcare professionals participated in three focus groups. We analysed the data thematically. Guba's Model of Trustworthiness was used to ensure rigour.

*Results:* Our findings revealed strategies for communicating about prognosis. Assessing patient emotions and knowledge and providing patients with clear prognostic information emerged as prominent strategies. Healthcare professionals proposed communicating frankly about the consequences of not treating osteosarcoma, treatment limitations, metastases and poor prognoses. They also suggested presenting prognostic information in a staged approach, normalising death, and not specifying life expectancy. In addition, informing patients that a palliative amputation would help with pain management emerged as a strategy for instilling hope. Various patient, provider and disease factors were identified as challenges when discussing prognosis.

*Significance of the Results:* Deviations from Western research findings emphasized the need for studies exploring prognostic communication in cross-cultural encounters. Our study highlighted the need for creative and thoughtful approaches to communicating sensitive information in cross-cultural clinical settings.

**Keywords:** prognosis; patient-provider communication; cancer; osteosarcoma; cross-cultural

## INTRODUCTION

Effective prognostic communication with patients is a prerequisite for treatment decision-making and future planning that is commensurate with patient preferences (Robinson et al., 2008). However, communicating about prognosis is widely documented as a challenging task (Back et al., 2008; Hagerty et al., 2004; Lamont & Christakis, 2003; Russell & Ward, 2011). Patients typically have varied preferences regarding prognosis information (Innes & Payne, 2009) that are sometimes complicated by cultural and family expectations and demands (Russell & Ward, 2011). In addition, the medical literature provides conflicting directives. Some studies indicate that patients want and need detailed information, and other studies report that patients want to limit their discussions about poor prognoses (Back et al., 2008).

This study was conducted with healthcare professionals working in a cross-cultural clinical setting in KwaZulu-Natal, South Africa. The study is part of a larger project aimed at developing an evidence-based practice guideline for communicating with Zulu patients diagnosed with osteosarcoma. The Zulu people are indigenous and place great value on traditional belief systems and oftentimes prefer a family-centred model of medical decision-making (Russell & Ward, 2011) especially when the proposed surgical treatment option is amputation (Chapter 4). A 2012 study revealed that 66.67% of the patients presenting at the study site with osteosarcoma between 2009 and 2011 already had metastatic disease (Ferreira & Marais, 2012). Healthcare professionals (HCPs) therefore find communicating prognosis to be especially challenging in this cross-cultural context as patients present late for treatment and tend to practice systems of healing and decision-making that are different to the Western medical system.

Prognostic communication literature often advocates the patient-centred approach proposing individualised assessments of what patients want to know (Back & Arnold, 2006; Ngo-Metzger et al., 2008). A staged approach to providing prognostic information (Del Vecchio Good et al., 1990) and respecting the fact that patients sometimes prefer to maintain some ambiguity about the future (Innes & Payne, 2009), has also been recommended. Prognostic information needs to be varied not only between individuals but also for a given individual over time (Russell & Ward, 2011). Patients have also indicated that even when they wanted detailed information, they preferred to negotiate the extent,

format, and timing of the information they received (Hagerty et al., 2004). The healthcare professionals in this study may experience difficulties in implementing these proposed strategies. Given the late presentation of patients at the study site, HCPs have to communicate diagnostic and treatment information urgently. The treatment options are closely related to patients' understanding of their prognosis and the outcomes resulting from various approaches to treatment. This paper explores the strategies used and challenges faced when communicating about prognosis in this cross-cultural clinical setting.

## **METHODS**

### **Study Setting**

This study was conducted at a tertiary hospital in the province of KwaZulu-Natal (KZN), South Africa. The hospital forms part of the national public health system that serves more than 80% of the South African population. The majority of the patients receiving services at this hospital are of Zulu origin. Zulu patients speak isiZulu, one of South Africa's 11 official languages, while healthcare professionals mostly speak English or Afrikaans. The hospital's Tumour, Sepsis and Reconstruction Unit (TSR), dedicated to the treatment of musculoskeletal tumours, is the only one of its kind in Western KZN and services a population of more than 3.5 million people.

### **Research Design and Methods**

We used a qualitative exploratory descriptive contextual design. We gathered data from three separate focus group interviews with orthopaedic consultants and registrars; allied health professionals including dietitians, occupational therapists, physiotherapists, and a social worker; and nurses from the orthopaedic and oncology outpatient clinics and wards. The focus group interview schedule was piloted with a social work colleague who has experience with working with cancer patients in the study setting. Questions explored how HCPs discuss prognosis with patients and also investigated how HCPs responded to questions from patients regarding prognosis if they chose not to discuss prognosis with patients.

## Participants and Sampling

The TSR Unit uses a multidisciplinary team (MDT) approach to managing patients diagnosed with osteosarcoma. The MDT comprises the orthopaedic consultants and registrars, the allied health professionals (physiotherapists, dieticians, occupational therapists, social workers, clinical psychologists) and orthopaedic and oncology nursing staff. We used census sampling and invited all these members of the MDT to participate in the focus groups. Twenty-three HCPs participated and five were not available due to scheduling constraints. Demographic information regarding participants is presented in Table 1 in order to contextualise the findings. Four Zulu healthcare professionals participated in the study thus emphasising the fact that medical encounters are largely culturally discordant at this tertiary hospital.

Table 1: Focus group demographic information (n=23)

Orthopaedic consultants and registrars	n=9
Registered nurses from orthopaedic wards, orthopaedic clinic, oncology clinic and pain service	n=5
Allied health professionals (physiotherapists, occupational therapists, dieticians, social worker)	n=9
Gender	
Males	n=8
Females	n=15
Ethnic Group (South Africa)	
White	n=13
Indian	n=4
African (Zulu)	n=4
Coloured	n=2

### **Data Collection, Analysis and Trustworthiness**

The second author, an independent researcher with qualitative expertise and with no prior knowledge of the participants conducted the focus group interviews. The interviews ranged in duration from 54 to 95 minutes and were audiotaped and transcribed verbatim. We used thematic analysis (Braun & Clarke, 2006) to analyse the data. The primary researcher and the focus group interviewer independently coded the data, and themes were then discussed and agreed upon. Themes were further independently reviewed by two qualitative research experts. Following multiple discussions with all three qualitative experts, themes were then finalised. The data analysis process was an iterative one. Guba's Model of Trustworthiness was used to ensure the rigour of the data collection and analysis processes (Lincoln & Guba, 1985; Shenton, 2004).

### **Ethical Approval and Considerations**

We obtained ethical approval for the study from the Biomedical Research Ethics Committee at the University of KwaZulu-Natal. Participation was voluntary, and written informed consent was obtained from all participants.

## **RESULTS**

The findings highlighted the specific strategies that HCPs reported using when discussing prognosis with Zulu patients diagnosed with osteosarcoma. The challenges that the study population encountered with regard to this prognostic discussion are also outlined. Participants reflected on the transformative nature of the focus groups (De Laine, 2000) as it created an opportunity for reflection on practice, and co-construction of culturally relevant strategies for communicating prognosis.

### **Strategies for managing the prognostic discussion**

This theme highlighted the strategies that the participants reported using in managing the prognostic discussion.

#### *Strategy 1: Assess patient emotions and knowledge*

HCPs indicated that they first enquired about patients' thoughts, fears, and impressions of the future.

*So I try to first find out what are their thoughts, what are they scared about, what are they feeling is going to happen and patients do know, especially prognosis, they do know when the end is near...*

*Strategy 2: Provide patients with realistic prognostic information*

Participants indicated that they informed patients about the prognostic consequences of not treating the osteosarcoma and also preferred to communicate honestly about treatment limitations, metastases and poor prognoses. The late presentation of patients and additional time required for cultural practices meant that HCPs had to share prognostic information urgently in order to fast-track treatment decision-making.

*Strategy 2.1: Inform patients about the prognostic consequences of not treating osteosarcoma*

HCPs informed patients that if left untreated, the cancer would spread and the patient would not survive. Patients requiring amputation typically requested to go home to consult traditionally and perform rituals if indicated, thus causing treatment delays. HCPs were therefore especially direct with these patients. Participants sometimes phrased this discussion by informing patients that if nothing was done this would be bad and if the amputation was done there was a chance of survival.

*I tell them that if left untreated it can spread and it will kill you.*

*I am saying if we do nothing it's bad, if you do something there is a chance of a good result.*

*Strategy 2.2: Inform patients about treatment limitations*

Participants informed patients about treatment limitations. They explained the nature of osteosarcoma to patients and informed patients that this type of cancer was not curable. Participants cautioned against telling patients that amputation could cure due to the possibility of recurrence.

*And then I typically explain that this cancer is not curable... osteosarcoma... if you leave it untreated it will kill you...*

Participants reported that they informed patients that even with surgery the cancer could recur. HCPs reiterated that patients had to return within six months and then annually to check for cancer recurrence.

*...it might spread later, you know even if we take it out now and we do an amputation now it does not mean that the cancer can't come back.*

*Strategy 2.3: Inform patients that they have metastases*

When patients had metastases, HCPs informed them that the condition was not curable but that amputation could help with pain. Patients were informed that limited intervention was possible due to the metastases.

*...if we know that it's a metastatic disease and it is not curable to tell them that it has spread already, we can do something about the pain that they have in the leg and the amputation will help for that pain for example but it has already spread and we can't do much about that.*

*Strategy 2.4: Inform patients about a poor prognosis*

HCPs highlighted being honest with patients about the terminal nature of the disease if the osteosarcoma was reasonably expected to result in the death of the patient within a short period of time. The period of time was not specified.

*I personally do tell people if they have a terminal disease that it's so...*

*Strategy 3: Use a staged approach*

Some of the allied health participants indicated that they dealt with prognosis in stages because the condition entailed long-term treatment. They focused on immediate goals and if the disease progressed, goals were adjusted to maintenance or palliative care.

*I would deal with it in phases because as we said it is a long term treatment and we are going to wait and see. For now your issue is this so our goals will be this. If it became worse, then we are going to change our goals to either maintenance or palliative care.*

*Strategy 4: Normalise death*

Participants approached talking to patients about dying by trying to normalise death. HCPs told patients that everyone is going to die and extended this explanation by indicating that they too could die at any time. Participants indicated that they could not specify when the patient would die. They informed patients that it could be a long time and that they could die from something else as well.

*...I can drive out of the hospital and you know get into an accident and die and you may still survive for quite a long time after that, so everyone is going to die...*

*Strategy 5: Do not specify a time frame*

Participants reported informing patients about poor prognoses but emphasised that patients should never be informed of their life expectancy. Some participants indicated that they would not know how to respond to a question about life expectancy.

*I never tell them what the life expectancy is.*

## **Challenges related to communicating about prognosis**

Although the participants were able to propose a number of strategies for communicating about prognosis, the prognostic discussion presented a number of challenges that HCPs did not know how to resolve. These challenges are described in terms of patient, healthcare provider and disease communication factors.

### *Patient Factors*

HCPs reported that patients' emotional responses varied from being in denial to being overly optimistic. Participants were also concerned that patients would view treatment as futile when they were informed of poor prognoses. They had experienced that informing a Zulu patient about a poor prognosis in relation to cancer often resulted in these patients not returning to the hospital. HCPs hypothesized that this was possibly due to patients believing that they were going to die regardless. Participants also experienced that patients stopped listening when they were informed of poor prognoses.

*...of course some patients are in denial, some patients are overly optimistic...*

*...once we start saying no you are going to die because of cancer then they are not going to come back to you.*

Participants observed that patients did not ask about prognosis and indicated that some patients may not want prognostic information. Participants also noted that they would want to know the odds of surviving but that Zulu patients had never asked them about the odds of survival.

*...you know if someone tells me okay you have got cancer, it hasn't spread, if we do an amputation that is potentially curative, my thing will be okay what's the chances of that being curative? You know that would be my first question. So what are my odds? No one has ever asked me that.*

### *Healthcare Provider Factors*

Competency concerns and lack of training regarding communicating about prognosis were reported. Allied health professionals experienced that there was unclear communication of prognostic information.

*From a physio side it can be a bit difficult when patients ask you am I going to die from this you know... whereas not being fully medically trained in that aspect we can't always answer those questions for patients.*

*...the problem is nobody tells you, say this and then say that...*

Certain role expectations emerged amongst the HCPs with regard to who should communicate with patients regarding prognosis. Nurses were of the opinion that it was ethical procedure for doctors to communicate the prognosis to patients. They indicated that they often interpreted prognostic information for doctors.

*...call the doctors and they would explain...*

*...you always let the doctor tell the patient the prognosis but we're always standing there...*

HCPs had varied perspectives regarding discussing prognosis with patients. Some were of the opinion that patients should determine how much they wanted to know. Other participants were unsure of whether to discuss poor prognoses with patients. They were concerned that informing patients accordingly could be adding to the bad news of the diagnosis and result in loss of hope. Some HCPs expressed discomfort about talking about prognosis whereas others felt that they would be withholding the truth if they did not inform patients about a poor prognosis. Discussing prognosis was especially challenging when HCPs had to inform patients requiring a palliative amputation that

despite the amputation they would still have limited life expectancy. They were guarded as they did not want to create false hope.

*I know there are some people that would say you mustn't tell people if they are terminally ill, that they are going to die.*

*I don't feel comfortable talking about prognosis...*

*I find prognosis being the most difficult one to deal with when they say for a palliative amputation...*

HCPs reported struggling with the timing of the prognostic communication. Zulu patients often insisted on going home to consult with the elders and perform rituals after being informed about treatment options especially when this entailed amputation (Chapter 4). This left HCPs in a difficult position regarding the timing of informing patients regarding prognosis especially when a delay in treatment would result in a poor prognosis. Participants were concerned that when patients went home they would be preoccupied with being told about a poor prognosis instead of focusing on consulting the decision-makers regarding proposed treatment options.

*You know as soon as they get home they say, the Doctor said I am going to die. And then eventually even if the decision-maker at home or the family sits down and asks about the options, the (patient) keeps saying no, I am going to die... the Doctor told me. (The patient) is now against whatever they (the family) are saying.*

### *Disease Factors*

Allied health professionals reported on the unpredictable and aggressive nature of osteosarcoma and its progression. They indicated that discussing prognosis was difficult because the condition changed

so quickly. Treatment could start with rehabilitation and dealing with functional issues which then progress to palliative care very quickly.

*In my view of prognosis... I don't know that it can be discussed with the patient because it is an osteosarcoma, it can change from the one stage to the other very quickly...*

## **DISCUSSION**

The data revealed several strategies for managing the prognostic discussion with Zulu patients and highlighted a number of challenges that HCPs were not able to resolve. Due to the late presentation of patients at the study site, HCPs felt compelled to communicate the urgency of treatment with patients and this typically included communicating prognostic information. Despite the uniqueness of the setting and participants' competency and training concerns, all the proposed strategies have been supported in the literature.

HCPs recommended assessing patient emotions and knowledge by asking them open-ended questions (Back et al., 2008). They then advocated that patients should receive realistic information about the prognostic consequences of not treating the osteosarcoma, treatment limitations, metastases, and poor prognoses. This strategy, referred to as realism, can facilitate sound medical decision-making for both patients and HCPs (Back & Arnold, 2006). However, taking the realistic approach without structuring the conversation and demonstrating empathy can be perceived as being uncaring (Back & Arnold, 2006). Participants reported that they attempted to phrase information positively.

Participants also proposed the strategy of normalising death by talking openly about it and even mentioning the self in relation to death. A willingness to talk about death and doing so in a skilful manner without fear has been emphasised (Sinclair, 2006; Wenrich et al., 2001). Participants preferred not to communicate estimations of life expectancy which is in line with general practice (Daugherty & Hlubocky, 2008) and clinical practice guidelines on communicating prognosis which recommended that HCPs should avoid being exact about time frames (Clayton et al., 2007).

The allied health professionals proposed a staged approach to communicating prognosis (Del Vecchio Good et al., 1990; Back et al., 2005; Back & Arnold, 2006; Clayton et al., 2007). This

strategy may be challenging at the study site as patients typically present late for treatment (Ferreira & Marais, 2012) leaving HCPs with the challenging task of communicating diagnosis, treatment and prognosis in close succession or simultaneously. A staged approach may be more useful for patients that present with localised or metastatic disease that is amenable to surgical management.

The strategy of instilling hope did not overtly emerge from the data. However, participants' tendency to inform patients that a palliative amputation would help with pain management has been described as a means of instilling hope (Clayton et al., 2005). Patients have reported that when HCPs emphasised what could be done, e.g. pain and symptom control, this fostered hope (Baile et al., 2000; Clayton et al., 2005). Hope therefore is not exclusively dependent on cure (Back et al., 2008) and should be offered at all stages of the disease (Barclay et al., 2007; Kirk et al., 2004).

Participants also reported on challenges to the prognostic communication process that they could not resolve. They highlighted Zulu patients' emotional responses, their beliefs that treatment would be futile and their tendency to withdraw when poor prognoses were communicated. These reported responses may be associated with Zulu patients' cultural and health beliefs regarding cancer (Chapter 3). The isiZulu word for cancer, *umdlavuza*, means something that destroys everything or something that cannot be stopped (Chapter 3). Participants further indicated that Zulu patients never asked about prognosis or the odds of surviving. This is in contrast to Western research which showed that most cancer patients wanted some degree of prognostic awareness (Innes & Payne, 2009), with metastatic cancer patients wanting detailed prognostic information (Hagerty et al., 2004). Patients' reported tendency to never ask about survival rates is also significantly different from Western trends (Hagerty et al., 2004). However, most surveys regarding patient preferences for detailed prognostic information have been conducted on English-speaking patients. Little is known about the prognostic communication preferences of ethnically diverse populations (Mitchison et al., 2012).

The HCPs identified a number of challenges that pertained specifically to them. They highlighted competency and training deficits (Butow et al., 2002; Hancock et al., 2007; Russell & Ward, 2011) and role expectations regarding who communicated prognosis (Reinke et al., 2010). Furthermore, HCPs could not agree on whether patients should be given prognostic information (Innes & Payne, 2009). Reasons for preferring nondisclosure centred on HCPs' discomfort regarding

disclosing prognosis (Baile et al., 2000; Hancock et al., 2007; Kirk et al., 2004; Mack & Smith, 2012) and concerns that prognostic disclosure would result in negative emotional outcomes for patients (Hancock et al., Mack & Smith, 2012) and would destroy hope (Back et al., 2008; Finlay & Cassarett, 2009; Russell & Ward, 2011). Disclosing a palliative amputation was highlighted as a particular challenge. HCPs preferring prognostic disclosure were concerned about withholding the truth from patients and argued that patients should be truthfully informed of their prognosis (Hancock et al., 2007; Wenrich et al., 2001). Being clear about the palliative or curative goals of treatment and specifying the outcomes that can be improved by the treatment have been recommended (Clayton et al., 2007). Mack et al. (2007) found no evidence that prognostic disclosure resulted in negative emotional outcomes or made patients less hopeful. In fact, research showed that honesty about prognostic information maintained and sometimes increased hope even in patients with advanced disease (Mack & Smith, 2012).

HCPs were also unsure of when to give Zulu patients prognostic information. They often went home to discuss treatment options with family decision-makers, and HCPs were concerned that they would fixate on the poor prognosis if they were given prognostic information before going home. Prognostic information should however be provided when there are requests or expectations that are inconsistent with clinical judgement (Clayton et al., 2007), as in this case when patients go home to consult with decision-makers and often delay returning to the hospital (Chapter 4). Furthermore, discussing prognosis facilitates treatment decision-making (Cartwright et al., 2014; Clayton et al., 2007). Patient knowledge of prognosis has been shown to play a significant role in making appropriate treatment choices (Weeks et al., 1998).

With regard to disease factors, allied health professionals reported that the unpredictable nature of osteosarcoma complicated the prognostic discussion. As the majority of patients presenting at the study site have metastatic disease (Ferreira & Marais, 2012), the progression-free survival rate for these patients is poor and the condition is usually incurable requiring palliation (Errani et al., 2011). Furthermore, in patients with localised disease the 5-year survival rate is 60 to 70% (Errani et al., 2011) with a 30 to 35% chance of local or systemic recurrence (Bacci et al., 2005). There are

therefore survival and disease progression rates available which the allied health professional staff may not be aware of as they have not been medically trained.

### **Limitations of the Study**

Firstly, all those that were eligible to participate were approached but some MDT members were not available at the time of data collection. Secondly, discipline specific focus groups were conducted which may have limited interprofessional synergy and data outcomes. Lastly, the use of other qualitative data-gathering may have enriched the data.

### **RECOMMENDATIONS FOR FUTURE RESEARCH**

The study findings provided information on what is said and why it is said however, further investigation is required to explore how it is said. Deviations from Western research findings emphasized the need for studies exploring prognostic communication in cross-cultural encounters. Contextual research on patients' preferences and suggestions on how to communicate about prognosis emerged as a prominent area for future research. Research exploring patients' experience of the proposed strategies would also assist in refining these strategies.

### **CONCLUSION**

This paper explored strategies used and challenges faced when communicating about prognosis in this cross-cultural clinical setting. Patients at this study site present late for treatment, and therefore have to receive diagnostic, treatment and prognostic information within close succession or simultaneously. In addition, this cross-cultural clinical setting requires that healthcare professionals integrate cultural beliefs and practices into their management of patients. Healthcare professionals proposed strategies for responding to these unique conditions. They expressed concerns regarding cultural competency and highlighted a lack of training regarding prognosis communication. However, they came up with strategies that are well documented in the literature. They chose to be innovative and relied on experiential knowledge.

Importantly, various patient, disease and healthcare provider factors that posed challenges to the prognostic communication process were also outlined. HCPs did not necessarily have solutions to

these challenges, however some of the factors highlighted demonstrated participants' sensitivity to cultural aspects of patient care. Furthermore, Zulu patients were reported to respond differently to prognostic information as compared to Western findings. The strategies reported on in this paper will contribute to the evidence-based practice guideline for communicating with Zulu patients diagnosed with osteosarcoma. Our study highlighted the uniqueness of this cross-cultural setting and the need for creative and thoughtful approaches to communicating sensitive information in cross-cultural clinical settings.

### **ACKNOWLEDGEMENTS**

We acknowledge the participants, Dr Wilma ten Ham-Baloyi and Mr Kegan Topper for reviewing the qualitative data, and Prof William Ventres for commenting on this manuscript.

### **DECLARATION OF CONFLICTING INTERESTS**

The Authors declare that there is no conflict of interest.

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### **Part 3: Conducting In-depth Interviews with the Zulu Patients**

The third part of this study addresses the third requirement for evidence-based practice, namely accessing patient preferences. The aim was therefore to obtain patient-based data by conducting in-depth interviews with Zulu patients regarding how the diagnosis, treatment and prognostic aspects of osteosarcoma is communicated to patients, their understanding of the diagnosis and treatment of osteosarcoma as well as their experience of the communication of these components. Furthermore, we accessed participants' descriptions of the role of culture in the management of this life-threatening illness. Part 2 highlighted the healthcare providers' voices and Part 3 illuminates the voices of our Zulu patients diagnosed with osteosarcoma. Chapter six is prepared in the submission format required for the journal *Ethnicity and Health*.

**Chapter 6: Communication across the osteosarcoma disease trajectory:  
Patients' factual, emotional and cultural accounts**

Brown O., Aldous C., Van Rooyen D., Marais LC.

**To be submitted to Ethnicity and Health**

## **Communication across the Osteosarcoma Disease Trajectory: Patients' Factual, Emotional and Cultural Accounts**

### **Abstract**

Patients' accounts of the process of receiving information regarding the diagnosis, treatment and prognosis of cancer in cross-cultural clinical settings are underreported. This study explored how the diagnosis, treatment and prognosis were communicated to patients and what patients understood about their diagnosis and treatment. Furthermore, we examined the patients' experiences of this communication and the role of culture in managing the condition. We used a qualitative case study approach with in-depth interviews that were analysed thematically. Data were verified using Guba's model of trustworthiness. Our results revealed that patients were relatively well-informed regarding diagnosis and treatment information. Perceptions of and emotional responses to the diagnosis and treatment of osteosarcoma as well as rich descriptions of the cultural and health beliefs, cultural decision-making processes and rituals practiced emerged. Findings also highlighted the importance of providing adequate information regarding diagnosis and treatment side-effects. The variability within a culture strongly emerged in this study reinforcing the importance of not stereotyping based on pre-existing knowledge of a cultural group. Participants also recommended integrating traditional and Western practices and accommodating patients' traditional preferences. The findings of this study will make a meaningful contribution to the development of an evidence-based practice guideline for culturally competent patient-provider communication with Zulu patients diagnosed with osteosarcoma.

Keywords: patient-provider communication; patient emotions; patient perceptions; patient knowledge; cultural considerations; cross-cultural clinical settings

## **Introduction**

Patients' accounts of the process of receiving information regarding the diagnosis, treatment and prognosis of cancer in cross-cultural clinical settings are underreported. The South African literature is especially scant in this regard (Herselman 1996; Lourens 2013; Mullin, Stewart, and Eremenco 1998). This study tries to address that problem. It focuses specifically on Zulu patients diagnosed with osteosarcoma. The Zulu people are indigenous to Southern Africa. They tend to follow traditional approaches to health and illness. In the eastern South African province of KwaZulu-Natal, where the majority of the province population is Zulu, 70% of patients consult traditional healers prior to visiting physicians or other practitioners trained in a Western model (Puckree et al. 2002). Indigenous South Africans commonly understand illness as being caused by supernatural forces, triggered by punishment from the ancestors, witchcraft or disequilibrium in social relationships, among other reasons (Lourens 2013; Mdonolo, De Villiers, and Ehlers 2003; Vorobiof, Sitas, and Vorobiof 2001). Zulu patients often prefer a family-centred model of medical decision-making (Vorobiof, Sitas, and Vorobiof 2001).

Clinical observations and research conducted (Chapters 3, 4, 5) at the study site highlighted various cultural dimensions that play a significant role in the management of Zulu patients diagnosed with osteosarcoma. In addition, the majority of patients presenting at the study site already have locally advanced or metastatic osteosarcoma which negatively affects treatment options and outcomes for survival (Ferreira and Marais 2012). Osteosarcoma is the most frequent primary solid malignancy of bone and is derived from primitive mesenchymal cells. Untreated osteosarcomas can result in local and/or metastatic disease progression (Ritter and Bielack 2010). Despite advances in treatment of osteosarcoma, survival is dependent on diagnosis prior to progression beyond localised

disease (Federman et al. 2009). Other challenges identified at the study site included the high risk of relapse despite adequate multi-modal treatment as well as poor prognostic outcomes.

This study is part of a larger research project aimed at developing an evidence-based practice guideline for culturally competent patient-provider communication with patients diagnosed with osteosarcoma (Brown et al. 2016). Clinical opinion was explored via focus group interviews which were conducted with healthcare professionals at the study site. This paper presents the voices of the Zulu patients receiving treatment for osteosarcoma. The aim of our study was therefore to explore and describe 1) how the diagnosis, treatment and prognostic aspects of osteosarcoma are communicated to patients, 2) their understanding of the diagnosis and treatment of osteosarcoma, 3) their experience of the communication of these components, and 4) the role of culture in the management of this life-threatening illness.

## **Methods**

### ***Study Setting***

This study was conducted at a tertiary hospital in the province of KwaZulu-Natal (KZN), South Africa. The study site forms part of the national public health system that serves more than 80% of the South African population. The healthcare system in KZN uses a referral system and specific referral patterns are followed. Patients may present at their local clinic or district hospital and may then be referred to a regional or tertiary hospital depending on the nature of the presenting problem. The KZN Department of Health has a transport system which brings patients from the local hospital to the tertiary facility. However, patients still have to transport themselves from home to their local hospital in order to access the hospital transport. Patients may travel as far as 450 kilometres to receive tertiary services. The Tumour, Sepsis and Reconstruction Unit that specialises in the treatment of musculoskeletal

tumours and the Oncology Department at the study site serve a population of approximately 3.5 million people.

KwaZulu-Natal has a population of 10.9 million people of a total South African population of 54 956 900 million (Statistics South Africa 2015). More than half of the province is rural (Rural Health Factsheet 2015), unemployment rates are high (Rural Health Factsheet 2015, Statistics South Africa 2016) and 56.6% of the KZN population live below the upper-bound poverty line (R620 per capita per month in 2011 prices (Rural Health Factsheet 2015). Exact statistics are not available but it is estimated that more than 80% of the KwaZulu-Natal population is Zulu. The Zulu people speak isiZulu, one of South Africa's 11 official languages. Medical encounters are largely culturally discordant at this tertiary hospital. HCPs receive medical training mostly in English or at some universities in Afrikaans and the majority of healthcare professionals are not of Zulu origin.

### ***Research Design and Method***

We used a qualitative descriptive case study design and conducted in-depth individual interviews with Zulu patients. The interview schedule was piloted to ensure that the appropriate data would be elicited for the purpose of the study. Questions explored how diagnosis, treatment and prognosis were communicated to the patient; what patients understood about their diagnosis and treatment; their experience of the communication; and the role of culture in managing the condition.

### ***Participants and Sampling***

Convenience sampling was used to gather participants for the study. Adult Zulu patients diagnosed with osteosarcoma were approached to participate. Patients were accessed from a record held at the Tumour, Sepsis and Reconstruction Unit that treats patients with

musculoskeletal tumours. Four participants agreed to participate in the research. One of the participants lived locally; another lived 78km from the hospital and the remaining two lived 159km away. Patient information is presented in Table 1.

Table 1: Patient Information

	Gender	Age	Occupation	Traditional Belief system	Religious Affiliation	Type of surgery
Participant 1	Male	27	Unemployed	Yes	Christian	Amputation
Participant 2	Male	24	Unemployed	Yes	Christian	Amputation
Participant 3	Female	33	University student	Yes	Christian	Limb salvage
Participant 4	Male	22	Unemployed	Yes	Christian	Amputation

Participants 1 and 3 were diagnosed in 2011 and now attend the Oncology Department at the study site for regular follow up. Participant 2 was diagnosed in 2014 and Participant 4 was diagnosed in 2014 but only had an amputation in 2016.

***Data Collection, Data Analysis and Trustworthiness***

Patients were contacted by isiZulu speaking fieldworkers and invited to participate in the study. Skilled interviewers conducted in-depth interviews in isiZulu using a semi-structured interview schedule. Interviews were audio-taped, transcribed verbatim and translated into English and back translated to check for accuracy of translations.

The data were analysed using thematic analysis (Braun and Clark 2006). An experienced qualitative researcher independently coded and analysed the data. Guba's model of trustworthiness with its four criteria was utilized to ensure rigour (Lincoln and Guba 1985; Shenton 2004).

### ***Ethical Approval and Considerations***

Ethical approval was obtained from the Biomedical Research Ethics Committee at the University of KwaZulu-Natal. The interviewer explained the research to participants and ensured that participation was voluntary, that written informed consent was obtained and that the principles of confidentiality and anonymity were upheld. The cover letter which included the consent form was available in isiZulu.

### **Results**

Eight themes emerged from the transcript analysis. Each theme is described and accompanied by illustrative verbatim quotations.

#### ***Theme 1: The Zulu patient's account of how the diagnosis was communicated***

All patients were informed that diagnostic testing was required. Patients were either informed of their diagnosis after diagnostic testing or warned of the possibility of a cancer diagnosis before commencing diagnostic testing, and then informed that the tests confirmed the diagnosis.

*Oh, they told me that they discovered that I had cancer from the tests that they had conducted on me. [P1]*

*Before I did any tests, they said they suspect that I might have osteosarcoma, but they said they won't say that it is so without running some tests. The tests came back positive. [P2]*

Patients reported on the factual knowledge received regarding the cause of osteosarcoma, the common age at diagnosis, and the fact that that they had cancer of the bone.

*I was told was a random cancer that could happen to anyone, but it was mostly found in people whose ages ranged from birth to twenty five, which was when I had found out at age twenty five. [P1]*

*They told me that this cancer that I'm suffering from is cancer of the bone... [P4]*

*They told me that there are different types of cancers. For instance, in my case it was osteosarcoma, which is cancer of the bone. [P2]*

Patients were provided with knowledge regarding metastases and the possible recurrence of osteosarcoma. Patients were informed when they had metastases. The education regarding recurrence provided at the time of diagnosis prepared patients who were later diagnosed with lung metastases.

*Before they amputated my arm, they said it has spread quite rapidly. [P4]*

*They told me that it's possible for the cancer to spread... That happened to me...*

*The cancer spread to the lung. [P2]*

Patients reported that HCPs warned them of possible bad news, checked their readiness to receive the diagnosis, attempted to offer privacy when communicating the diagnosis, and offered patients reassurance.

*...so they took me out of the ward and took me to a room that looked almost like this one. It was just the doctors and me as the patient when they told me. [P1]*

*They told me that they have something to tell me about the disease that I have.*

*They asked if I was okay with being told at that time. I said its fine they can tell me. They then drew the curtains because I was in the ward. [P4]*

### ***Theme 2: The Zulu patient's account of how treatment options were communicated***

Patients indicated that communication about treatment was prioritised hence they understood the urgency of intervening.

*The way they took it is that they made it a priority that also made me understand that if you don't take it as an immediate priority it will jeopardize your life quickly. [P1]*

Patients reported that HCPs educated them about surgical treatment options and chemotherapy. Patients indicated that when they required amputation they were informed that this was the only surgical option. When both limb salvage and amputation were possibilities,

the risks and benefits of each option and the requirement of chemotherapy before surgery were explained to patients. A patient indicated that he was informed that the best 'life-saving' option for him was amputation.

*...the only way is to operate and remove the cancer from the infected area so that it does not spread [P1]*

*They then said it's better if they remove the arm because the tumour was enlarged... Amputate the whole arm. [P4]*

*There were two options when it came to the operation. It was either they would amputate my leg or do a limb salvage... They presented them well... They told me the pros and cons of amputation. Same thing with limb salvage. [P2]*

*...the specialist there told me that the safest way to save my life was to amputate the affected limb... [P1]*

*They told me that it's possible that the cancer returns, but if I do chemotherapy, it will be able to control the cancer. [P4]*

*I was told that I was going to undergo chemotherapy for three months. And then after that, go for an operation. [P2]*

Patients reported that oral and intravenous chemotherapy as well as the side-effects of chemotherapy were explained to them.

*...there's chemotherapy... chemotherapy drip and chemotherapy tablets. [P3]*

*So to cure it or to prevent it from spreading and to control it, you have to go through chemotherapy. Chemotherapy does this to a person's body and these are the side effects... Hair loss, weight loss, vomiting a lot. [P3]*

Patients indicated that they were informed that they would develop metastases without surgical intervention and chemotherapy.

*...if they did not amputate and if I had not gone for chemo, it would easily have spread. [P1]*

*...they said there is a way to treat it so that it doesn't spread to another part of the body, because if you leave it for too long without it being treated, it spreads to other parts of the body. [P2]*

Patients conveyed that they were advised that if metastases were detected, they may require further surgical intervention. One of the patients with lung metastases was informed that he could either have surgery or he could have chemotherapy.

*Because when it had spread in the lungs, they gave me options to choose from...*

*Because I had gone to chemotherapy two or three times, they gave me an option to either have an operation or go back to chemotherapy on my fourth visit. [P3]*

*The cancer spread to the lung. I went for an operation again. [P2]*

Although the treatment options of radiation and oral chemotherapy were mentioned to some of the patients, these seemed to not have been elaborated on.

*Then with radiation and the other form of chemotherapy tablets, they (healthcare professionals) didn't dwell on it a lot because they were focusing on the drip (intravenous chemotherapy). [P3]*

### ***Theme 3: The Zulu patient's account of how prognosis was communicated***

Patients indicated that prognosis was explained in terms of the threat of recurrence and metastases. They were advised that the cancer would metastasize to the lungs, chest, and other organs if left untreated. Patients were also informed that the cancer could recur despite having been treated hence regular follow ups and diagnostic testing was essential.

*Every three months I go for a CT scan, bone scan, X-rays, everything. [P3]*

*They told me that it's possible for the cancer to spread to another part of your body despite the fact that the affected area has been treated. [P2]*

*After undergoing chemo and having the operation, you carry on doing tests and going to X-rays and CT scans. I had gone to do a CT scan and it showed that the cancer has now spread to the lung. That's how I found out. [P2]*

#### ***Theme 4: The Zulu patient's understanding of the information provided***

Patients were able to relay factual information regarding the diagnosis of osteosarcoma, the role of diagnostic tests, the concept of metastases and the implications thereof. With regard to treatment information, patients had knowledge of the surgical options and the reason why amputations were performed above the affected area. They also knew about oral and intravenous chemotherapy, the role of chemotherapy in managing metastases, and the side-effects of chemotherapy. Patients' knowledge of radiotherapy as a treatment option was limited.

*The cancer that I have is bone cancer. [P3]*

*According to my knowledge, it attacks the bones. [P2]*

*What happened was they took me to theatre and cut out that bone and took it for testing. After about twenty days they came back and told me that it was cancer...*

*[P1]*

*And with amputation, as they had seen where the cancer was, they would need to amputate above that affected area so that they can be certain that the cancer affected area was fully removed. [P1]*

*It had grown a lot in one place. So they decided to amputate. Then I went through chemotherapy. I did three cycles of chemotherapy. Six cycles once, six cycles twice, six cycles thrice. [P3]*

*With chemo, they are trying to kill the diseases that are still in your body, so if those diseases are still active they need to clear them with chemotherapy in order that they do not spread further. [P1]*

***Theme 5: The Zulu patient's perception of the diagnosis and treatment options***

Perceptions of the diagnosis varied from associating the diagnosis with death and dying at the time of receiving the diagnosis, to viewing cancer as a serious illness that is not necessarily associated with death as more information was provided. Perceptions varied regarding whether cancer is curable.

*You associate cancer with death up until you get mental help and until then, you will always associate it with death. [P1]*

*In my opinion, when it is detected early, I can say that it is curable. [P2]*

Perceptions of treatment varied from an association with death and dying to being viewed as a means of cure. Amputation specifically was perceived to have far-reaching consequences with regard to self-esteem, intimate relationships, future planning and the ability to earn a living, and was associated with a feeling of incompleteness. A positive view of chemotherapy was reported as it was understood as a means of curing cancer.

*...they will amputate my leg, I was the type of person who used my mobility to make a living... how was I going to make a living once they amputate my leg. I have dreams of furthering my studies but how was I going to continue with that?  
...the moment you lose a body part, there are some dreams you had that needed*

*your entire body that you will never accomplish. So even your self-esteem gets affected especially for us younger men who are still chasing ladies. [P1]*

***Theme 6: Zulu patients' emotions regarding the diagnosis and treatment options***

Emotional responses to the diagnosis included sadness and the fear of being judged, pitied or excluded. The amount of information impacted significantly on emotional responses. Patients who did not understand anything about cancer tended to have a neutral reaction. Receiving information was reported to increase hope and improve adjustment to the diagnosis. Efforts to move towards an acceptance of the diagnosis in order to prevent a negative attitude also emerged from the data.

*So when you think of explaining this to the next person, you feel as though this person will either judge you or pity you hence at times you feel unaccepted and decide not to talk about it. [P1]*

*When I found out I have cancer I cried day and night because at the end of the day we as the youth, you still have your dreams and want to have a family and all that. [P1]*

*...when I was told that I have this disease, I was not scared. I didn't have any problem because I didn't understand anything about cancer. [P2]*

*At that time, I didn't understand much about cancer... I took it lightly... But as time went on, it dawned on me that I have this disease, cancer, so I have to accept it and get a solution so that I don't have a negative attitude. [P3]*

Emotional responses to treatment information included a loss of hope and feeling traumatised especially in response to amputation and the side-effects of chemotherapy. Another patient responded positively to treatment information in that he readily agreed to surgery as it was associated with the cancer being excised.

*...once you do chemotherapy you may discover that you may not be able to conceive and have children, that is very traumatizing. [P1]*

### ***Theme 7: Zulu patients' experience of the communication process***

Zulu patients were satisfied with the content and process of information provided regarding diagnosis and treatment. Patients reported receiving sufficient information that was relayed in a manner that facilitated patient understanding. A need for more information regarding the side-effects of chemotherapy was expressed.

*They were clear and explained everything perfectly. [P2]*

*I don't have any suggestions because I don't see anything more that could be done to improve. Things are okay as they are... I think everything is fine as it is.*

*[P2]*

*They should be honest and explain everything to you because we won't be the same... [P1]*

Positive emotional outcomes of hope and adjustment to diagnosis resulting from the communication approach taken were reported.

*I'm still okay, it's going to be controlled. They gave me hope and motivated me.*

*[P3]*

*...the doctors' approach and the way they explained everything to me are what helped. [P1]*

Patients also commented on the quality of communication related to care in general and relayed that HCPs took an interest in them and communicated patiently, openly and respectfully.

*When the doctor came to check on me, he didn't just sign and leave. He would ask me how I slept, how is the pain, what I need in terms of painkillers...*

*Things like that. They were very patient with me. [P3]*

*The doctor will also ask if I am in pain. If I am in pain, I tell him and then he helps to relieve the pain. [P4]*

*I was always happy because when I got to the ward the nurses explained everything in detail regarding everything that I had to do and the things that they will do. [P4]*

*Respect is there in everyone, because I see old doctors and old nurses who respect me. They don't say because you are young, we won't give you any attention or respect you. They respect me and that makes me happy. [P3]*

***Theme 8: Cultural aspects for consideration when treating Zulu patients***

This theme focuses on Zulu patients' cultural and health beliefs, cultural decision-making processes, rituals and patients' proposal for combining Western and traditional approaches to managing illness.

*Cultural and health beliefs*

Individual differences with regard to cultural and health beliefs emerged. Patients indicated that Zulu people use traditional medicines and consult with the ancestors when they are ill. The importance of not abandoning tradition was emphasised as medical tests cannot always identify the cause of illness resulting in patients needing to go home to practice their cultural traditions. The belief that something has possibly been cast on the patient in the form of witchcraft to cause the illness was also highlighted. Even though all participants indicated on the demographic questionnaire that they followed traditional belief systems, some preferred Western medicine over traditional medicine. Patients who preferred Western medicine indicated that their families favoured traditional belief systems.

*We, as African people believe in that when we get illnesses and diseases we believe in things like traditional medicines and ancestors and all those things. [P1]*

*At home yes, we do follow tradition, but I don't believe in them. I don't believe that they will help me because at home they also gave me options that I should go to a traditional healer who will help me, and do one, two and three. [P3]*

Diagnosis did not seem to require cultural intervention. Traditional beliefs came to the fore when treatment, specifically amputation, was discussed. This was explained in terms of the Zulu culture dictating that a person cannot be buried with missing body parts hence Zulu people prefer not to donate their organs. In addition, if the person had left home intact, they cannot return home missing a limb. Those that adhered to the traditions had to return home to consult with the elders and observe traditions as going to theatre without doing so could result in negative consequences like not regaining consciousness or becoming paralysed. For one of the patients, the experience of negative life events which were associated with bad luck necessitated following traditional practices to prevent further bad luck.

*I don't think traditions have much to do with that because when I discovered that I had cancer there was nothing I had to do tradition wise, but when I found out that I was going to be amputated, was when traditions came into play. [P1]*

Another patient believed in prayer and did not believe in traditional medicine and hence did not consult with a traditional healer.

*So you see if I believed in traditional healers and medicine, I would have gone to a traditional healer... because I don't believe in traditional medicine, I believe in prayer... [P2]*

One of the patients expressed that he preferred Western medicine and perceived that Western medicine would be more likely to save his life than traditional medicine.

*...as long as my life is saved because if I had believed in a traditional healer, maybe I wouldn't be here today.*

#### *Consultation and decision-making*

Patients reported on the role of consultation in decision-making with regard to surgical procedures. Consultation entailed approaching the elders in the family who then usually consulted with the ancestors. Consulting well with the ancestors was associated with surgical success. Consultation with traditional healers was also advocated to obtain clarity. One of the patients that strictly adhered to Zulu traditions reported on how he was first taken to the traditional healer to ascertain the accuracy of the Western diagnosis. Emphasis was placed on consulting with an honest traditional healer. His elders found an honest traditional healer that confirmed that the patient's leg could not be saved. The traditional healer found that the patient's cancer had nothing to do with traditions and encouraged the patient to have surgery.

*Normally what they do first is they take you to the traditional healers to ascertain that what the Western doctors had diagnosed was accurate, and luckily they found an honest traditional healer who told them it was true that the leg could not be saved. [P1]*

Three of the participants involved their families in the diagnosis and treatment but made their own decisions regarding surgery. These patients' families respected their decision

to use Western medicine and supported them. None of these patients consulted a traditional healer even though one was explicitly advised to do so.

*Yes, I did speak to my family. But they didn't have a problem with my decision. They preferred the hospital... It was my decision. It's just that I had to tell them about what was going on. The decision was mine. [P2]*

*Yes, I did tell my aunty that I stay with that I'm considering amputating my arm... My aunt said she's scared, but if I have made that decision, it's fine as long as I will get the help that I need. [P4]*

*...at home they also gave me options that I should go to a traditional healer who will help me I said okay, fine, but he will not help me. My decision is that I must go to the hospital, where I will get help the right way. [P3]*

### *Rituals*

The patients referred to rituals that were performed to ensure the success of their surgeries. Families performed rituals regardless of patient preferences. Only one of the patients indicated that no rituals were performed before the operation. Patients referred to a ritual involving the burning of incense to inform the ancestors about the surgery and to ask for a successful outcome. It was reported that traditional healers usually asked patients to wait a month before doing surgery so that they could perform Zulu rituals in order to cure the patient before the surgery.

*But I believe they did burn incense when I was at hospital. My family believes in ancestors... Maybe they were just asking that the ancestors work with the doctors while I was on the operating table. [P2]*

*My aunt burned the incense so that when I go to the operating room, everything will go well. [P4]*

One of the patients reported that when he arrived home after the operation, he was not allowed to enter the home. A ritual was first performed outside the yard so that he could enter the yard cleansed. The purpose of the cleansing ritual was to remove things like bad luck (e.g. cancer diagnosis) and evil spirits from the patient and his family and to prevent this bad luck from entering the home. The cleansing rituals were performed with Zulu medicine and chickens. An animal is used, either a chicken or a goat to present the ill person to the ancestors. The ancestors are asked to welcome the affected person and watch over them so that the person can continue with life and deal with their condition. The ancestors have to be informed that the patient now has one instead of two limbs. When the patient entered the yard an announcement was made that the ritual had been done and he was then welcomed.

#### *Combining Western and traditional belief systems*

Patients indicated that it is important to acknowledge the existence of the traditional but to also understand that some diseases need Western medical treatment. Participants stated that Zulu patients should not abandon their traditions but that they should know that there are diseases like cancer, TB, and HIV that require Western treatment. At the same time it was proposed that culture and traditions should not be abandoned as there are times that a disease is related to something that needs traditional intervention.

*We can't turn our backs on the existence of such things (witchcraft, traditional medicine, ancestors), yes, they do exist, they can also make you sick and kill you but we must also understand that there are those diseases that need the treatment of Western medicines and doctors... So what I'm saying is one should not abandon their traditions but they must know that there are diseases such as cancer, TB, HIV and the like. [P1]*

Patients acknowledged traditional rituals like burning incense and consulting traditional healers but also advised that people should not hesitate to seek Western medical assistance if the need arose. Conversely, it was proposed that the Western medical professionals should allow patients to observe their traditions.

*If a person feels that they are not feeling well, even if they perform traditional rituals and burn incense and consult traditional healers... if the illness forces them to go to hospital, they mustn't be scared to go to hospital because they will get help. [P4]*

## **Discussion**

Our study accessed patients' accounts of the process of receiving information regarding the diagnosis, treatment and prognosis of osteosarcoma and retrieved cultural information pertaining to the management of the condition. This study revealed unique findings that not only contribute substantially to improved management of Zulu patients diagnosed with osteosarcoma but also provide HCPs with feedback regarding the aspects of communication that are going well.

Some of our unique findings pertain to Zulu patients' extensive understanding of the diagnosis of osteosarcoma, diagnostic procedures, the treatment options applicable to treating osteosarcoma and the side-effects of chemotherapy. This finding is in contrast to local (Lourens 2013) and international (Makaryus and Friedman 2005) research findings where patients lacked information about their diagnosis and treatment. Furthermore, Zulu patients' reports of receiving sufficient information are also in contrast to local research findings at another South African tertiary hospital (Vangu 2010).

Our study also highlighted patients' varied perceptions and emotional responses to diagnosis and treatment and exposed the difference in perception between HCP and patient perceptions of amputation. Exploring and acknowledging patients' perceptions of treatment options may help to resolve this discrepancy. Importantly, receiving information had a positive influence on patients' perceptions of and emotional responses to the diagnosis. Receiving sufficient information regarding chemotherapy and its side-effects may also assist with patient adjustment especially as patients highlighted a lack of information pertaining to the side-effects of chemotherapy and demonstrated negative responses to this treatment. Patients expressed a need for improved communication of the side-effects of chemotherapy. Cancer patients typically want more detailed information about treatment side-effects (McLoughlin and Oosthuizen 1996).

A significant contribution of this paper is embedded in Zulu patients' descriptions of their cultural and health beliefs, the decision-making practices in their families, and the rituals practiced. Despite reports that indigenous African people are obligated to comply with cultural rules (Yen and Wilbraham 2003; Chapter 4), some of the patients in this study made their own decisions regardless of family recommendations regarding rituals and consultation with traditional healers. Individual differences within cultural groups (Epner and Baile 2012; Kagawa-Singer, Valdez Dadia, and Surbone 2010; Mullin, Stewart, and Eremenco 1998;

Norman 1996) can be expected. Although knowledge of cultural practices and preferences is a prerequisite for culturally competent communication, patients should not be stereotyped based on this knowledge.

Furthermore, Zulu patients encouraged integrating Western and traditional approaches to managing illness and proposed that HCPs should accommodate patients' cultural preferences. It is not uncommon for patients from indigenous populations, especially when diagnosed with a life-threatening illness like cancer, to integrate Western medicine and traditional healing (Broome and Broome 2007; Lourens 2013; Muhamad, Merriam, and Suhami 2012; Struthers and Eschiti 2004; Yen and Wilbraham 2003). The intra-cultural variability (Engebretson, Mahoney, and Carlson 2008) noted in this study and the recommendation for the accommodation of patients' cultural preferences (Bensing 2000) necessitates a patient-centred approach to medicine.

### ***Limitations of the Study***

Patients were asked to provide retrospective accounts of their experiences and the interviews were conducted at one point in time and not as the disease process unfolded. Furthermore, there were considerable challenges with regard to locating participants and this limited the size of the sample. Although a Zulu interviewer ensured that patients could express themselves in their own language, the interviewer already knew what patients meant with regard to some of the cultural aspects that were discussed and hence these were not further explored. Zulu patients' accounts of how prognosis was communicated are limited and require further exploration.

## **Conclusion**

This study pioneers an understanding of Zulu patients' knowledge and experience of patient-provider communication regarding the diagnosis, treatment and prognosis of osteosarcoma. The findings highlighted the complexity of working in cross-cultural clinical settings. HCPs have to be conversant with cultural beliefs and practices but still be able to accommodate the individual voices of patients. They have to develop an understanding of their patients' experience of their illness and its treatment including their perceptions of and emotional responses to the diagnosis, treatment and prognosis. HCPs also have to be sensitive to the fact that their perceptions about illness management may differ considerably from patients' perceptions. It is therefore important to invite the individual patient to discuss their experience. Working in cross-cultural clinical settings also requires a flexibility which allows for the integration of Western and traditional approaches to healing if this is the patient's preference. In addition, HCPs have to ensure that they provide adequate information regarding diagnosis and treatment, especially side-effects of treatment. The findings of this study will make a meaningful contribution to the development of an evidence-based practice guideline for culturally competent patient-provider communication with Zulu patients diagnosed with osteosarcoma. Our findings stressed the need for a patient-centred approach to developing and implementing evidence-based practice guidelines when working across cultural boundaries.

## **Acknowledgments**

We acknowledge the participants, Dr Wilma ten Ham-Baloyi for independently coding the qualitative data, and Prof William Ventres for commenting on this manuscript.

## Declaration of Conflicting Interests

The Authors declare that there is no conflict of interest.

## Funding

This research was not funded.

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## **Part 4: Developing the Evidence-Based Practice Guideline**

This section comprises the evidence-based practice guideline which is the culmination of this research project. Evidence from the integrative literature review, focus groups with healthcare professionals and in-depth interviews with the Zulu patients were used to develop the evidence-based practice guideline. Chapter seven presents the manuscript that will be submitted for publication. However, the complete evidence-based practice guideline with the reviewer comments and scores and a more detailed description of the methods is presented in Appendix H. The items from the AGREE II (Appraisal of Guidelines, Research and Evaluation) appraisal instrument that were used to score the guideline are presented in Appendix I.<sup>1</sup>

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**Chapter 7: Culturally competent patient-provider communication with Zulu patients diagnosed with osteosarcoma: An evidence-based practice guideline**

Brown O., Aldous C., Van Rooyen D., Marais LC.

**To be submitted to Current Oncology**

## **Culturally competent patient-provider communication with Zulu patients diagnosed with osteosarcoma: An evidence-based practice guideline**

### **Guideline Summary**

**Guideline aim:** The aim of this guideline is to present healthcare providers treating Zulu patients diagnosed with osteosarcoma with evidence-based recommendations that can facilitate culturally competent communication regarding the diagnosis, treatment and prognosis of osteosarcoma.

**Methods and materials:** The AGREE II (Appraisal of Guidelines, Research and Evaluation) appraisal instrument was used as a guide for developing the evidence-based practice guideline. An integrative literature review, focus groups with healthcare providers and in-depth interviews with Zulu patients were conducted to gather the evidence for the evidence-based practice guideline. The guideline was reviewed by an expert panel using the AGREE II tool.

**Setting:** This guideline was developed for healthcare providers communicating with adult Zulu patients diagnosed with osteosarcoma.

**Results:** The guideline specifies generic aspects such as the awareness, knowledge, skills and provider attitudes required for culturally competent communication as well as the type of healthcare system that can support and cultivate such communication. The guideline then details specific recommendations for communicating the diagnosis, treatment and prognosis of osteosarcoma to Zulu patients.

**Conclusion:** Healthcare providers will require cultural competence and communication training to facilitate the implementation of the guideline. Limitations with regard to the body of evidence are recognised. Despite these limitations, this guideline is the first of its nature in the South African context and provides valuable insights regarding the ingredients required in order to work effectively in cross-cultural clinical settings. Evidence-based practice can contribute to improving culturally competent communication with cancer patients receiving treatment at culturally discordant healthcare facilities.

Key words: evidence-based practice guideline; cancer; osteosarcoma; cultural competence; communication; cross-cultural; Zulu

## 1. INTRODUCTION

Communicating the diagnosis and prognosis of cancer is widely documented as challenging tasks.<sup>1-10</sup> Furthermore, ensuring that patients understand their treatment options is considered good practice.<sup>11</sup> Performing these tasks in cross-cultural clinical settings complicates patient-provider communication.<sup>12</sup> Culture plays a significant role in how patients' health-related values, beliefs and behaviours are shaped, and affects how patients and communities approach the diagnosis and treatment of cancer as well as their trust in healthcare providers and institutions.<sup>13,14</sup> Culture also affects professionals' and institutions' approach to minority patients and contributes substantially to disparities in access to healthcare for minority and underprivileged patients.<sup>14,15</sup> An evidence-based practice guideline would contribute significantly to improving culturally competent communication with cancer patients receiving treatment at culturally discordant healthcare facilities.

This guideline was developed for healthcare providers communicating with adult Zulu patients diagnosed with osteosarcoma. The Zulu people are indigenous and reside in the predominantly rural South African province of KwaZulu-Natal. They speak isiZulu, one of South Africa's 11 official languages. This province has an overall population of 10.9 million (of a total South African population of 54 956 900 million), the majority of which is classified as Zulu.<sup>16</sup> The focus on osteosarcoma resulted from observations in clinical practice of the significant role that cultural factors play including extensive familial, ancestral and/or traditional healing consultations and rituals before agreeing to certain treatment option in the management of osteosarcoma. In addition, research findings indicated that the majority of patients presenting at the study site already have locally advanced or metastatic disease.<sup>17</sup> Other observations in clinical practice related to delayed presentation included denial and/or underestimation of the seriousness of the condition. Our research with healthcare providers and Zulu patients at the study site confirmed that cultural considerations were paramount when treating Zulu patients diagnosed with osteosarcoma (Chapters 3-6).

Despite advances in treatment of osteosarcoma, survival is dependent on diagnosis prior to progression beyond localised disease.<sup>18</sup> The late presentation of patients therefore limits treatment options and results in very poor prognosis.<sup>17,19-22</sup> Healthcare providers in this setting are therefore expected to simultaneously inform patients of the diagnosis of osteosarcoma, the significant limitations with regard to treatment options, and prognostic considerations in a culturally sensitive manner that engenders cooperation in the patient while allowing them the opportunity to fulfil their cultural obligations. This evidence-based

guideline was developed to address the shortcomings that were identified at the study site, where healthcare encounters were largely culturally discordant.

## **METHODS AND MATERIALS**

The AGREE II (Appraisal of Guidelines, Research and Evaluation) appraisal instrument was used as a guide for developing the evidence-based practice guideline.<sup>23</sup>

### **2.2. Scope and Purpose**

The aim of this guideline is to present healthcare providers treating adult Zulu patients diagnosed with osteosarcoma with evidence-based recommendations that can facilitate culturally competent communication regarding the diagnosis, treatment and prognosis of osteosarcoma. The review question read: How is culturally competent patient-provider communication best delivered by healthcare providers to adult Zulu patients diagnosed with osteosarcoma? The targeted patient population are adult Zulu patients diagnosed with osteosarcoma.

### **2.2 Stakeholder Involvement**

The guideline was developed by one of the members of the multidisciplinary team working with Zulu patients diagnosed with osteosarcoma. The developer is a content expert with methodological experience in both quantitative and qualitative research.

Furthermore, the healthcare providers working in a multidisciplinary team context with Zulu patients diagnosed with osteosarcoma participated in focus groups and Zulu patients' views and preferences were investigated using in-depth interviews.

The evidence-based practice guideline was developed for use amongst healthcare providers (doctors, nurses and allied health professionals) working with Zulu patients diagnosed with osteosarcoma. The doctors working in the Orthopaedics Department are the first port of call for these patients. Nurses working in orthopaedic and oncology outpatient clinics and wards have the most contact with Zulu patients diagnosed with osteosarcoma. Allied health professionals working with this patient group include physiotherapists, clinical psychologists, social workers, occupational therapists and dieticians.

### **2.2 Rigour of Development**

An integrative literature review was conducted to review the existing evidence. Details of the integrative literature review process are available in Brown et al.<sup>24</sup> In addition, focus groups

with healthcare providers (Chapters 3-5) and in-depth individual interviews with Zulu patients (Chapter 6) were conducted in order to contextualise the guideline. The approach taken therefore reflects the general consensus in the literature that evidence-based practice typically includes three key components namely, research-based evidence available from the literature, clinical expertise and patient preferences.<sup>25,26</sup> The recommendations were developed using content analysis. A comprehensive and frequently used hierarchy system (Table 1) was applied to rate the evidence.<sup>27</sup> The guideline development process was supervised by content and methodological experts. In addition, the guideline was also reviewed by an expert panel which consisted of five content and methodological experts.

Table 1: Rating System for the Hierarchy of Evidence for Intervention/Treatment Questions<sup>27</sup>

Level I (strongest evidence)	Evidence from a systematic review or meta- analysis of all relevant randomized controlled trials (RCTs) Evidence from evidence-based clinical practice guidelines based on systematic reviews of RCT's
Level II	Evidence obtained from at least one well-designed RCT
Level III	Evidence obtained from well-designed controlled trials without randomization (quasi-experimental study)
Level IV	Evidence from well-designed non-experimental studies (case-control, correlational, cohort studies)
Level V	Evidence from Systematic reviews of descriptive or qualitative studies
Level VI	Evidence from a single descriptive or qualitative study
Level VII	Evidence from the opinion of authorities and/or reports of expert committees

## 2. GUIDELINE RECOMMENDATIONS

The recommendations are based on levels IV, VI and VII evidence from the integrative literature review, focus groups with healthcare providers and patient interviews. Cultural competence has varied definitions but seems to require the acquisition, integration and application of awareness, knowledge, skills and attitudes regarding cultural differences in order to effectively deliver expert care that meets the unique cultural needs of patients; to manage and reduce cross-cultural misunderstanding in discordant medical encounters; and to

successfully negotiate mutual treatment goals with patients and families from different cultural backgrounds.<sup>15,30-37</sup> The guideline first specifies generic aspects such as the awareness, knowledge, skills, and provider attitudes required for culturally competent communication as well as the type of healthcare systems that can support and cultivate such communication. The guideline then details specific recommendations for communicating the diagnosis, treatment and prognosis of osteosarcoma to Zulu patients. Table two provides a summary of the guideline recommendations and the associated levels of evidence.

Table 2: Guideline Recommendations and associated Levels of Evidence

Guideline Recommendations		Levels of Evidence
Healthcare provider awareness	Develop contextual awareness	Level IV, VI, VII
	Develop self-awareness	Level VI, VII
	Develop interpersonal awareness	Level VI, VII
	Develop awareness of cultural expectations in the healthcare setting	Level VI, VII
Healthcare provider knowledge	Acquire knowledge of broader contextual factors	Level VI, VII
	Acquire context specific knowledge	Level VI, VII
	Acquire self-knowledge	Level VII
	Acquire knowledge of the patient's culture	Level VII
Healthcare provider skills	Acquire and apply cross-cultural communication skills	Level VII
	Ensure patient understanding	Level IV, VI, VII
	Manage differences in the patient-provider encounter	Level IV, VI, VII
	Build the patient-provider relationship	Level IV, VI, VII
	Conduct a comprehensive patient assessment	Level VI, VII
	Accommodate the patients' family	Level VI, VII
	Instil and maintain hope regardless of the disease stage	Level VI
Healthcare provider attitudes	Take responsibility for cultural aspects of health and illness	Level VI
	Take responsibility for combating discrimination in healthcare settings	Level VI

Guideline Recommendations		Levels of Evidence
	Take responsibility for learning about the Zulu culture	Level VI
	Be willing to learn from patients	Level VII
	Be open to change and growth	Level VI
	Be culturally sensitive	Level VI, VII
	Be willing to listen	Level VI
	Develop and demonstrate respect for cultural diversity, for the patient's culture and their cultural values	Level IV, VI, VII
	Demonstrate respect for patients' spiritual and religious beliefs	Level VII
	Develop an appreciation of different health belief systems	Level VII
	Be willing to explore culture with individual patients	Level VII
	Validate different cultures	Level VII
	Engage in continual self-examination and self-reflection to examine one's own values and assumptions	Level VI, VII
	Be willing to adjust behaviours and attitudes	Level VII
	Reflect on own interaction with cultural groups in the clinical setting	Level VII
Culturally competent healthcare systems	Cultivate the characteristics of culturally competent healthcare systems	Level VI, VII
	Strategies employed by culturally competent healthcare systems	Level IV, VI, VII
Recommended strategies for communicating the diagnosis of osteosarcoma to Zulu patients	Provide patients with factual information	Level VI
	Set the stage for truth-telling	Level VI
	Engage in patient-centred communication	Level IV, VI, VII
	Engage in culture-centred communication	Level IV, VI, VII
	Facilitate understanding of the diagnosis	Level VI
Recommended	Provide patients with factual information	Level VI

Guideline Recommendations		Levels of Evidence
strategies for communicating the treatment of osteosarcoma to Zulu patients	Follow a specific process when discussing treatment	Level IV, VI, VII
	Strategies for responding to cultural factors associated with amputation	Level VI
	Strategies for responding to cultural and health beliefs that affect treatment	Level VI
Recommended strategies for communicating prognostic information pertaining to osteosarcoma with Zulu patients	Assess patient emotions and knowledge	Level VI
	Inform patients of the prognostic consequences of not treating the osteosarcoma	Level VI
	Inform patients of treatment limitations	Level VI
	Inform patients regarding metastases and treatment limitations result from the metastases	Level VI
	Inform patients of poor prognoses	Level VI
	Use a staged approach when patients have non-metastatic or minimally metastasised disease	Level VI

## 2.1 Generic requirements for culturally competent communication

### *Evidence-based rationale*

Generic requirements for engaging in culturally competent communication include the development of awareness, the acquisition of knowledge, the acquisition and implementation of skills and strategies and fostering certain attitudes.<sup>15,30</sup> The development and practice of culturally competent communication by individual practitioners and multidisciplinary teams is best fostered in the context of culturally competent healthcare systems. Culturally competent healthcare systems provide linguistically and culturally appropriate services and supportive policies, strategies and resources that promote culturally competent communication.<sup>38</sup>

### **3.1.1 Healthcare provider awareness**

Different types of **healthcare provider awareness** are required for working in cross-cultural oncology settings.

3.1.1.1 It is recommended that healthcare providers **develop contextual awareness** of:

- the country's socio-political history<sup>37</sup>
- the sociocultural factors that affect the patient-provider relationship<sup>38</sup>
- patient demographics in the service area<sup>39,40</sup>
- the role of gender in culture<sup>40,41</sup>
- the role of religion in culture<sup>40,41</sup>
- patients' level of education<sup>42,43</sup>
- patients' experiences of discrimination in clinical settings<sup>44</sup>
- dominant cultural narratives regarding health and illness<sup>45</sup>
- culturally constructed myths about cancer<sup>46</sup>
- cancer patients possibly combining allopathic and traditional medicine<sup>45</sup>

3.1.1.2 It is recommended that healthcare providers **develop self-awareness** of own:

- culture<sup>47</sup>
- cultural beliefs<sup>48</sup>
- belief systems<sup>49</sup>
- spirituality<sup>50</sup>
- cultural assumptions, biases and stereotypes<sup>14,38,47,49,51</sup>

3.1.1.3 It is recommended that healthcare providers **develop interpersonal awareness** of:

- inherent power differentials between patient and provider<sup>37</sup>
- interaction between patient and provider's culture<sup>47,52</sup>
- communication differences between cultures<sup>41,53</sup>

3.1.1.4 It is recommended that healthcare providers **develop awareness of cultural expectations in the healthcare setting** related to the:

- level of family involvement required<sup>49,54</sup>
- role of family in cross-cultural clinical settings<sup>15,40,54,55</sup>

### ***3.1.2 Healthcare provider knowledge***

Culturally competent communication requires the acquisition, integration and application of knowledge regarding the context, the self, and the patient's culture.

3.1.2.1 It is recommended that healthcare providers **acquire knowledge of broader contextual factors** pertaining to:

- racism, sexism, ageism<sup>48,56</sup>
- socio-political barriers to accessing healthcare<sup>14,51,57</sup>
- the impact of past and present racism<sup>51</sup>
- the role of gender in the communication process<sup>14</sup>
- the role of age in the communication process<sup>14</sup>
- patients' role expectations in the communications process<sup>14</sup>
- socio-historical cultural context<sup>14</sup>
- socio-cultural differences between self and patient<sup>51</sup>

3.1.2.2 It is recommended that healthcare providers **acquire context specific knowledge** of:

- the cultural groups attending services in the provider's clinical setting<sup>39,51,53,55,57,58</sup>
- serviced population's disease profiles, health disparities and treatment outcomes<sup>34,53</sup>
- cultural health-related needs and health-seeking behaviours<sup>51</sup>
- cultural approaches to illness and treatment<sup>38</sup>
- cultural meanings of cancer<sup>14</sup>
- patients' perception of their illness<sup>53</sup>
- influence of culture on how patient interacts with healthcare system<sup>49</sup>

3.1.2.3 It is recommended that healthcare providers **acquire self-knowledge** of own:

- culture<sup>45,51,53,57</sup>
- belief system<sup>51</sup>
- biases and stereotypes<sup>14,49,51,57</sup>

3.1.2.4 It is recommended that healthcare providers **acquire knowledge of the patient's culture**, specifically:

- the patient's health belief systems<sup>44,54,57</sup>
- the patient's traditional health system<sup>54</sup>
- the role of gender in decision-making<sup>39,54</sup>
- the role of family in decision-making<sup>39,54</sup>
- preferences regarding language used to discuss cancer<sup>15</sup>
- nonverbal communication standards<sup>15</sup>

### 3.1.3 Healthcare provider skills

The healthcare provider is expected to acquire, integrate and apply a variety of skills in order to successfully deliver culturally competent patient-provider communication.

3.1.3.1 It is recommended that healthcare providers deliver culturally and linguistically sensitive services by **acquiring and applying** the following **cross-cultural communication skills**:

- Engage in culturally sensitive communication recognising the values beliefs and practices of the patient and presenting the communication accordingly<sup>14,15,46,59</sup>
- Engage in culturally congruent communication which recognises that cultural variations exist between patient and HCP and engages in culturally sensitive and competent communication accordingly<sup>14,57</sup>
- Observe culturally appropriate nonverbal communication etiquette<sup>14</sup>
- Use congruent verbal and nonverbal communication<sup>14,57</sup>

3.1.3.1.1 It is recommended that healthcare providers **ensure patient understanding** by acquiring and applying the following communication skills and strategies:

- Provide clear,<sup>54, 57</sup> accurate,<sup>54,57</sup> open,<sup>43,44,50,60</sup> flexible,<sup>43</sup> and transparent<sup>50</sup> communication
- Provide information in the patient's language<sup>54</sup>
- Learn the language<sup>54</sup>
- Develop a vocabulary of terms familiar to the patient<sup>54</sup>
  - Include some basic isiZulu phrases in conversations [focus groups]
- Use language that patients can understand [focus groups]
- Use simple language<sup>37,42-44</sup> [focus groups]
- Encourage the patient to ask questions<sup>41</sup> [focus groups]
- Repeat information several times<sup>37</sup> [focus groups]
- Check patient understanding of information<sup>37,44,52,53,54,59</sup> [focus groups]
- Check what patients remember from previous explanations [focus groups]
- Do not use medical jargon [focus groups]

3.1.3.2 It is recommended that healthcare providers **manage differences in the patient-provider encounter:**

- Avoid stereotyping and generalisations<sup>14,34,38,51,53,54,57</sup> [focus groups]
- Do not make assumptions about patient race, nationality and language<sup>15</sup> [focus groups and patient interviews]
- Treat patients equally<sup>42,43</sup>
- Encourage patients to raise concerns about discrimination<sup>44</sup>
- Create a culturally safe and caring environment<sup>37,60</sup>
- Individualise patient care<sup>38,60</sup>

3.1.3.3 It is recommended that healthcare providers **build the patient-provider relationship:**

- Invest time in the beginning<sup>39,53,61</sup>
- Engage the patient<sup>57</sup>
- Build rapport<sup>37,41</sup>
- Gain patient trust<sup>28,41,43,46,57</sup>
- Respond to patients' emotions [focus groups & patient interviews]
- Actively engage patients in decision-making<sup>41,53,59</sup> [focus groups]
- Encourage and empower patients to raise trust issues<sup>44</sup>
- Address patients according to cultural preference<sup>57</sup>
- Recognise inherent power differentials<sup>57</sup>
- Be open about own cultural frame of reference<sup>45</sup>
- Acknowledge own cultural background to patients<sup>15</sup>
- Respond skilfully to cultural discordance<sup>57</sup>

3.1.3.4 It is recommended that healthcare providers **conduct a comprehensive patient assessment:**

- Assess patients' specific communication needs<sup>61</sup>
- Conduct a cultural assessment by actively exploring patients' culture:<sup>50,52,61</sup>
  - Invite patients to describe their cultural backgrounds<sup>58</sup>
  - Explore views on family and community in the healthcare context<sup>58</sup>
  - Explore cultural<sup>57</sup> and health beliefs<sup>49</sup>
  - Explore family expectations, feelings and concerns<sup>50</sup>
  - Explore level of family involvement required<sup>49</sup>

- Determine who the main decision-makers are (patient or family?)<sup>38,39</sup> [patient interviews]
- Explore preferences for truth disclosure<sup>15,49,53</sup>
- Explore patients' spiritual and religious beliefs<sup>15,50</sup>
- Ask patients about their disease process [focus groups]
  - Use Kleinman's eight questions<sup>28,58</sup>

3.1.3.5 It is recommended that healthcare providers **acquire and apply the skill of accommodating the patients' family:**

- Invest in and gain family trust<sup>42,57</sup>
- Communicate with extended family as per patient's directive<sup>57</sup> [focus groups]
- Afford the family maximum control possible if this is a patient need<sup>50</sup>

3.1.3.6 It is recommended that healthcare providers **instil and maintain hope regardless of the disease stage** by [focus groups]:

- Emphasising what **can** be done
  - Inform patients that a palliative amputation could help with pain management
- Reassuring patients of continued involvement of the multidisciplinary team
- Differentiating the different problems that would be addressed
- Explaining how the different problems would be addressed
- Avoiding the provision of false hope
  - Do not inform patients that amputation could cure due to the possibility of disease recurrence

#### ***3.1.4 Healthcare provider attitudes***

It is recommended that healthcare providers **cultivate and integrate** the following **attitudes** in order to facilitate culturally competent communication:

- Take responsibility for cultural aspects of health and illness<sup>38</sup>
- Take responsibility for combating discrimination in healthcare settings<sup>38</sup>
- Take responsibility for learning about the Zulu culture [focus groups]
- Be willing to learn from patients<sup>57</sup>
- Be open to change and growth<sup>60</sup>
- Be culturally sensitive<sup>15,38,60</sup>

- Be willing to listen<sup>60</sup>
- Develop and demonstrate respect for cultural diversity, for the patient's culture and their cultural values<sup>15,38,43,44,49,55,56,57</sup>
- Demonstrate respect for patients' spiritual and religious beliefs<sup>42</sup>
- Develop an appreciation of different health belief systems<sup>56</sup>
- Be willing to explore culture with individual patients<sup>53</sup>
- Validate different cultures<sup>58</sup>
- Engage in continual self-examination and self-reflection to examine one's own values and assumptions<sup>48,51,60</sup>
- Be willing to adjust behaviours and attitudes<sup>53</sup>
- Reflect on own interaction with cultural groups in the clinical setting<sup>53</sup>

### ***3.1.5 Culturally competent healthcare systems***

**Culturally competent healthcare systems** are a requirement for the delivery of culturally competent communication.

3.1.5.1 It is recommended that healthcare systems cultivate the following **characteristics**:

- Are responsive to individual needs and to how cultures are perceived<sup>46,51</sup>
- Promote and facilitate effective patient-centred communication<sup>51</sup>
- Respect cultural differences, and support effective care for diverse populations<sup>51</sup>
- Provide ethnic-specific services<sup>14</sup>
- Convert an awareness of disease prevalence into practices and policies<sup>34</sup>
- Develop and implement policies to support effective cross-cultural communication<sup>51,60</sup>
- Link with culturally competent agencies and community organisations that provide bilingual and bicultural navigation, promotions, and community health outreach services<sup>14</sup>
- Have adequate support services<sup>60</sup>
- Include traditional healers in patient care [focus groups]

3.1.5.2 It is recommended that healthcare systems employ the following cultural competence **strategies**:

- Use patient navigators<sup>32,39,41,57,62,63</sup>
- Use experienced and professional interpreters<sup>14,15,28,38,41,44,45,49,54,58</sup>

- Use culturally sensitive print, visual, and audio-visual media and electronic communication<sup>41,44,59</sup>
- Use images to assist providers when discussing cancer with patients<sup>37</sup> [focus groups]
- Monitor patient characteristics<sup>44</sup>
- Translate written communications<sup>38</sup>
- Provide language-concordant encounters<sup>44</sup>
- Provide patient-centred care<sup>62</sup>
- Consult communities on cultural needs<sup>37</sup>
- Integrate community resources into cancer care<sup>14</sup>
- Display images of people from cultural groups attending the service<sup>37</sup>
- Have ethnically similar staff visible<sup>37</sup>

## **2.2 Recommended strategies for communicating the diagnosis, treatment and prognosis of osteosarcoma**

The focus groups and patient interviews revealed specific strategies for communicating the diagnosis of osteosarcoma to Zulu patients. General recommendations for discussing treatment as well as proposed strategies for managing cultural factors that affect treatment are outlined. Prognosis discussion recommendations are less extensive but still provide some guidance on how to approach this challenging task.

### ***3.2.1 Recommended strategies for communicating the diagnosis of osteosarcoma to Zulu patients***

#### *Evidence-based rationale*

Communicating the diagnosis of cancer in cross-cultural clinical settings is documented as a challenging task.<sup>64</sup> Results from the focus group interviews with healthcare providers highlighted distinctive factors that complicate communicating the diagnosis of osteosarcoma to Zulu patients. The Zulu people generally view the cancer diagnosis as an ancestral punishment or resulting from witchcraft and have been socialised to associate a cancer diagnosis with a poor prognosis. The isiZulu word for cancer reflects these cultural health beliefs and presents a significant barrier as the meanings associated with this word significantly complicates the diagnosis discussion especially when a good prognosis is possible. The isiZulu word for cancer is *umdlavuza* and refers to something that ravages, destroys, or cannot be stopped. Furthermore, language barriers present a significant challenge

in this cross-cultural setting. The lack of availability of medical terms in isiZulu and the limitations with regard to the translatability of words into the patient's language significantly impacts patient understanding. Language barriers further manifest in the lack of access to professional interpreters. Communicating the diagnosis of osteosarcoma to the Zulu patients therefore requires an understanding of cultural and health beliefs and incorporating this knowledge into diagnostic conversations.

3.2.1.1 It is recommended that healthcare providers provide patients **with factual information** about their condition including [patient interviews]:

- Its name
- Prevalence
- Causes

3.2.1.2 It is recommended that healthcare providers **set the stage for truth-telling** by:

- Starting the diagnosis discussion right from the beginning [focus groups]
- Assessing how much the patient knows
- Warning patients a few times about possible cancer diagnosis [focus groups and patient interviews]
- Giving patient incremental information as the diagnostic process unfolds [focus groups]
- Informing patients of the reasons for diagnostic tests [focus groups and patient interviews]
- Warning patients before delivering bad news when the diagnosis is confirmed [focus groups and patient interviews]
- Warning patients by reminding them of earlier conversations of possible diagnosis [focus groups]
- Checking patients' readiness to receive the diagnosis [patient interviews]
- Offering privacy when communicating the diagnosis [patient interviews]
- Confirming diagnosis only once patient has been warned [focus groups and patient interviews]

3.2.1.3 It is recommended that healthcare providers **engage in patient-centred communication** by:

- Building a relationship with the Zulu patient (see 3.1.3.3) [focus groups]

- Spending time with the patient [focus groups]
- Offering the patient support [focus groups]
- Demonstrating a personal interest in the patient [focus groups]
- Assessing and addressing patient needs, emotions and coping [focus groups and patient interviews]
- Responding to patient questions about the diagnosis [focus groups]
- Assessing patients' reactions to the diagnosis [focus groups]
- Responding appropriately to patients' reactions to the diagnosis [focus groups]
- Managing the response of denial by [focus groups]
  - acknowledging that the diagnosis is difficult to accept
  - reinforcing the diagnosis
  - helping patients to accept the diagnosis
- Mobilising support by having a psychologist present when patients are informed of the diagnosis [focus groups]

3.2.1.4 It is recommended that healthcare providers **engage in culture-centred communication** by:

- Taking responsibility for improving communication (see also 3.1.3.1.1) [focus groups]
- Demonstrating an understanding of Zulu cultural health beliefs [focus groups]
- Reassuring patients that their diagnosis is [focus groups]:
  - not due to anything that they have done
  - not a punishment
  - not due to bewitchment
- Demonstrating a genuine interest in the Zulu culture by [focus groups]:
  - Asking patients questions about (see also 3.1.3.4)
    - their cultural practices
    - their religious practices
    - their understanding of the aetiology of the condition
    - how they want to manage the condition
    - their cultural health beliefs
- Offering patients the best care possible regardless of language discordance [focus groups]

3.2.1.5 It is recommended that healthcare providers **facilitate understanding of the diagnosis** by [focus groups]:

- Using visual aids
  - Use images, pictures and information brochures
- Explaining the stages of cancer
  - Educate patients regarding their stage of the disease
  - Educate patients about the effects of cancer in every stage
- Using metaphors
  - Use metaphors to explain concepts like cells, organs, tumours and metastases
  - Use patient-initiated metaphors

### ***3.2.2 Recommended strategies for communicating the treatment of osteosarcoma to Zulu patients***

#### *Evidence-based rationale*

Owing to the late presentation of patients for treatment at the study site, treatment options are limited and prognoses are often poor.<sup>17</sup> Healthcare professionals (HCPs) consequently have to simultaneously inform patients of the diagnosis of osteosarcoma as well as the significant limitations with regard to treatment options. A number of cultural factors have been identified with regard to discussing the treatment option of amputation with Zulu patients. Healthcare providers reported in the focus group interviews that Zulu patients' cultural beliefs dictate that they cannot become an ancestor if they have an amputation because their body is incomplete. The issue of post-amputation community exclusion was also raised. The patient interviews also revealed that cultural considerations become important when treatment, specifically amputation, is discussed. Focus groups and patient interviews further indicated other Zulu cultural and health beliefs that affect treatment such as the belief in traditional healing and the need to consult with cultural decision-makers before agreeing to treatment. The recommendations on how to communicate with Zulu patients regarding the treatment of osteosarcoma therefore take these cultural beliefs and practices into account.

3.2.2.1 It is recommended that healthcare providers **provide patients with factual information** pertaining to [focus groups and patient interviews]:

- Surgical treatment options
  - Limb salvage is explained if this is an option

- Amputation is discussed if it is the only option or in the case of borderline tumours
- Chemotherapy
  - Its purpose
  - When and how it will be used
  - Side-effects of chemotherapy (emphasised in patient interviews)
- Treatment of metastases (metastasectomies and/or chemotherapy)

3.2.2.2 It is recommended that healthcare providers follow this **process when discussing treatment** with patients:

- Delay providing treatment information until staging investigations are completed
- Inform patients about the prognostic consequences of not treating the tumour, e.g. metastases, shortened life-span [focus groups and patient interviews]
- Balance hope and honesty [focus groups] by
  - Communicating the urgency of intervening [patient interviews]
  - Offering patients reassurance [patient interviews]
- Ensure patient understanding by (see also 3.1.3.1.1) [focus groups]:
  - Using analogies
  - Using the stages of cancer to explain disease progression and realistic treatment options.
- Explore and manage patients' emotions associated with amputation and chemotherapy [patient interviews]

3.2.2.3 It is recommended that healthcare providers use these **strategies for responding to cultural factors associated with amputation** [focus groups]:

- Time the treatment discussion to prevent the patient from signing refusal of hospital treatment (RHT) before diagnostic testing is complete.
- When patients refuse amputation, offer patients other treatment options like chemotherapy and refer patients to other services like oncology, psychology, social work and dietetics.
- Mobilise support by having a psychologist present when patients are informed of that an amputation is required
- Expose patients to veteran osteosarcoma patients who have successfully adjusted to amputation

- Show newly diagnosed patients a video of patients with successful outcomes

3.2.2.4 It is recommended that healthcare providers use these **strategies for responding to cultural and health beliefs that affect treatment**:

- Initiate cultural discussions in order to fast track decision-making [focus groups]
- Demonstrate an understanding of patients' cultural beliefs by:
  - Acknowledging patients' need to discuss treatment with their family [focus groups]
  - Encouraging patients to engage in their cultural traditions and rituals [focus groups and patient interviews]
  - Encouraging patients to combine Western and traditional approaches [focus groups and patient interviews]
  - Respecting patients' cultural health beliefs and their desire to consult traditional healer [focus groups and patient interviews]
- Liaise directly with family and cultural decision-makers where possible [focus groups]
- Negotiate with patients to not go home and to rather invite a family member(s) to the hospital [focus groups]

### ***3.2.3 Recommended strategies for communicating prognostic information pertaining to osteosarcoma with Zulu patients***

Evidence-based rationale

Given the late presentation of patients at the study site, HCPs have to communicate diagnostic and treatment information urgently. The treatment options are closely related to patients' understanding of their prognosis and the outcomes resulting from various approaches to treatment.

3.2.3.1 It is recommended that healthcare providers **assess patient emotions and knowledge** by:

- Enquiring about patients' thoughts, fears, and impressions of the future [focus groups]

3.2.3.2 It is recommended that healthcare providers **inform patients of the prognostic consequences of not treating the osteosarcoma** [focus groups and patient interviews]:

- Inform patients of the likelihood of metastases if the osteosarcoma was not treated.

- Inform patients of the effect on survival if the osteosarcoma was not treated.

3.2.3.3 It is recommended that healthcare providers **inform patients of treatment limitations**:

- Explain the nature of osteosarcoma to patients and inform patients that this type of cancer is not curable [focus groups]
- Inform patients that even with surgery the cancer could recur [focus groups and patient interviews]
- Inform patients that they have to return within six months and then annually to check for cancer recurrence [focus groups and patient interviews]

3.2.3.4 When patients have **metastases**, it is recommended that healthcare providers inform patients that:

- That they have metastases [focus groups and patient interviews]
- The condition is not curable but that amputation could help with pain [focus groups]
- Treatment options are limited due to the metastases [focus groups]

3.2.3.5 It is recommended that healthcare providers **inform patients of poor prognoses**:

- Inform patients about the terminal nature of the disease if the osteosarcoma is reasonably expected to result in the death of the patient within a short period of time [focus groups]
- Normalise death [focus groups]
- Do not inform patients of the life expectancy [focus groups]

3.2.3.6 It is recommended that healthcare providers **use a staged approach** to communicating about prognosis [focus groups]. Given the late presentation of patients at this tertiary hospital, a staged approach may be more useful for patients that present with localised or metastatic disease that is amenable to surgical management.

- Communicate about immediate treatment goals and if the disease progresses, communicate about adjustments in treatment goals to for example palliative care.
- If treatment is working and cancer is remitting, communicate with patients about rehabilitation and resuming normal everyday activities.

### **3. LIMITATIONS**

There are limitations with regard to the body of evidence used to develop this guideline. These included the mostly low level evidence (Level VII) in the integrative literature review; the lack of availability of some of the healthcare providers at the time of data collection; patients' retrospective accounts of their experiences as the interviews were conducted at one point in time; and challenges experienced with regard to locating participants limited the size of the sample.

### **4. CONCLUSIONS**

Communicating with patients about cancer in cross-cultural clinical settings is widely recognized as a challenging task. This guideline offers guidance with regard to approaching this daunting task. It was developed based on evidence derived from an integrative literature review, focus groups with healthcare providers that work with Zulu patients diagnosed with osteosarcoma, and interviews with patients diagnosed with osteosarcoma. The research with healthcare providers and patients provided higher levels of evidence for some of the recommendations. Further development of this guideline needs to address the remaining limitations. Healthcare providers will require cultural competence and communication training in order to facilitate the implementation of the guideline. Despite the limitations of the body of evidence, this guideline is the first of its nature in the South African context and provides valuable insights regarding the ingredients required in order to work effectively in cross-cultural clinical settings. Evidence-based practice can contribute significantly to improving culturally competent communication with cancer patients receiving treatment at culturally discordant healthcare facilities.

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## Chapter 8: Synthesis and Discussion

### 8.1 Chapter Overview

This chapter revisits the rationale for the study and the aim and objectives of the research. A synopsis of the main findings of the study and the original contributions of the work is provided. The limitations of the study and recommendations for future research, training and policy development are also outlined. Practice implications are briefly revisited.

### 8.2 Rationale for the Study

Observations in clinical practice indicated that the management of osteosarcoma in Zulu patients requires a number of cultural considerations. In addition, patients typically present at the study site with locally advanced or metastatic disease.<sup>1</sup> Osteosarcoma is the most common primary cancer of bone, and the complexity of its treatment necessitates a multi-disciplinary approach.<sup>2</sup> The late presentation of patients and further delays stemming from patients' preferences to fulfil cultural practices results in treatment limitations and very poor prognosis.<sup>1-5</sup> Healthcare providers in this setting are therefore expected to simultaneously inform patients of the diagnosis of osteosarcoma, the significant limitations with regard to treatment options, and prognostic considerations in a culturally sensitive manner that engenders cooperation in the patient while allowing them the opportunity to fulfil their cultural obligations. Healthcare encounters at the study site are largely culturally discordant. This study therefore aimed to gather evidence which could inform the development of an evidence-based practice guideline. The aim of the guideline is to provide recommendations for engaging in culturally competent communication with adult Zulu patients regarding the diagnosis, treatment and prognosis of osteosarcoma.

### 8.3 Research Aim and Objectives

The overall aim of the study was to develop an evidence-based practice guideline for culturally competent patient-provider communication with Zulu patients with regard to osteosarcoma diagnosis, treatment and prognosis. The study had four objectives that cohered in order to meet the overall aim of the study:

**Objective 1:** Conduct an integrative literature review to gather evidence from previous research. The integrative literature review allows for the inclusion of studies with diverse methodologies.<sup>6</sup>

**Objective 2:** Gather evidence from healthcare providers. An exploratory descriptive contextual study design was used to investigate the approach taken by healthcare providers when discussing

osteosarcoma, its treatment and prognosis with Zulu patients as well as the cultural aspects considered during these discussions. A semi-structured focus group interview guide was used to elicit relevant information.

**Objective 3:** Gather evidence from Zulu patients. An exploratory descriptive contextual study of patients previously treated for osteosarcoma to explore patient understanding of the osteosarcoma diagnosis, its treatment and prognosis, and patient experience of patient-provider communication throughout the illness experience was conducted. Patients’ cultural descriptions related to the management of osteosarcoma were also elicited. Qualitative in-depth semi-structured interviews were conducted to gather this information.

**Objective 4:** Develop an evidence-based practice guideline for culturally competent patient-provider communication with osteosarcoma patients based on the evidence collected in Objectives 1, 2 and 3. The evidence-based practice guideline was developed by using the AGREE II (Appraisal of Guidelines, Research and Evaluation) appraisal instrument as a guide.<sup>7</sup>

#### 8.4 Schematic Representation of the Work

Figure 1 provides a summary of the chapter outline of the study as well as the process followed in developing the evidence-based practice guideline.

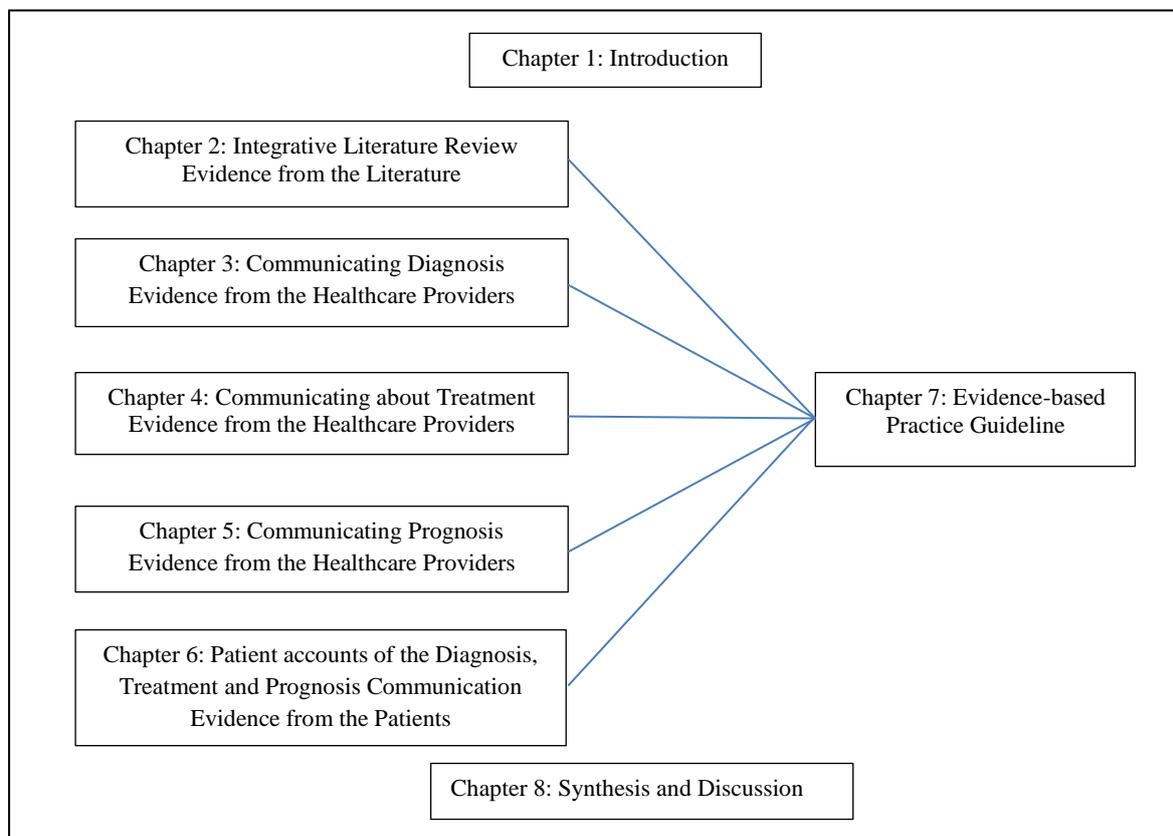


Figure 1: Schematic Representation of the Work

## **8.5 Summary of the Main Findings**

The integrative literature review provided directives on how to deliver culturally competent communication to adult cancer patients. It unpacked the awareness, knowledge, skills and healthcare provider attitudes and personal characteristics required for culturally competent communication. Characteristics and strategies of culturally competent healthcare systems required to support individual efforts and models of effective cross-cultural communication also emerged from the documents included in the review (Chapter 2). The grave need for scientifically rigorous research yielding higher levels of evidence in the field of cancer and culturally competent patient-provider communication was emphasised by the lack of quality evidence for all the themes that were presented in this integrative literature review. The main themes and subthemes are presented in Table 1.

Table 1: Delivering Culturally Competent Communication to Cancer Patients

<b>Themes</b>	<b>Sub-themes</b>
Healthcare provider skills	<ul style="list-style-type: none"> <li>• Communication skills</li> <li>• Managing difference in the patient-provider encounter</li> <li>• Skills required for building the patient-provider relationship</li> <li>• Ability to conduct a patient assessment beyond the biomedical</li> <li>• Accommodating the patient's family</li> <li>• Accommodating religion and spirituality</li> </ul>
Healthcare provider awareness	<ul style="list-style-type: none"> <li>• Contextual awareness</li> <li>• Self-awareness</li> <li>• Interpersonal awareness</li> <li>• Awareness of cultural expectations in the healthcare setting</li> </ul>
Healthcare provider knowledge	<ul style="list-style-type: none"> <li>• Context specific knowledge</li> <li>• Self-knowledge</li> <li>• Knowledge of patient's culture</li> <li>• Knowledge of broader contextual factors</li> </ul>
Culturally competent healthcare systems	<ul style="list-style-type: none"> <li>• Characteristics of culturally competent healthcare systems</li> <li>• Strategies employed by culturally competent healthcare systems</li> </ul>
Providers' personal characteristics and attitudes	<ul style="list-style-type: none"> <li>• Healthcare providers' personal characteristics</li> <li>• Healthcare providers' attitudes</li> </ul>
Models of effective cross-cultural communication	<ul style="list-style-type: none"> <li>• Kleinman's questions</li> <li>• The LEARN Model</li> <li>• The BELIEF Model</li> <li>• The Four Habits Model of Highly Effective Clinicians</li> </ul>

Following the integrative literature review, we conducted research with healthcare providers and Zulu patients. Most research and protocols for discussing sensitive information with patients are generic; few refer to considerations that are specific for the particular cross-cultural clinical setting. Although directions from these protocols are useful, evidence from our research could be used to develop recommendations for managing the unique challenges encountered in cross-cultural clinical settings. Evidence from the healthcare provider and patient studies can be classified as Level VI evidence. These studies broke contextual ground as it offered an African perspective of culturally competent patient-provider communication with cancer patients with specific reference to osteosarcoma. Care was taken to ensure methodological rigour as is discussed in Chapter one.

Our research with the healthcare providers produced a number of strategies for communicating with Zulu patients about the diagnosis, treatment and prognosis of osteosarcoma. These strategies also addressed cultural considerations and provided detailed information on the cultural factors that have to be taken into account when managing Zulu patients diagnosed with osteosarcoma (Chapters 2, 3, 4). Cultural factors included Zulu patients' beliefs about cancer and amputation, their need to access traditional healing and their requirements regarding collective treatment decision-making. Healthcare providers highlighted the importance of balancing respect for patients' cultural preferences with the need to expedite treatment decision-making in order to improve prognostic outcomes. Challenges encountered with regard to discussing diagnosis, treatment and prognosis were also outlined in these three chapters. In addition to confirming previously identified strategies and challenges, this study also unearthed unique strategies and challenges peculiar to this cross-cultural clinical setting. Despite the uniqueness of some of these strategies, they could be useful in other cross-cultural clinical settings where patients belong to collectivistic cultures, and observe traditions and other practices that are significantly different to Western medical approaches. Our findings also emphasised the vital importance of training healthcare providers on communication of sensitive information in cross-cultural clinical settings. Details of the strategies and complicating factors that emerged in terms of communicating diagnosis, treatment and prognosis are briefly outlined in Tables 2 and 3.

Table 2: Strategies for Communicating Diagnosis, Treatment and Prognosis

<b>Diagnosis</b>	
Set the stage for truth-telling	<ul style="list-style-type: none"> <li>• Start discussion right from the beginning</li> <li>• Assess how much the patient knows</li> <li>• Ask patients about their disease process</li> <li>• Warn patients a few times about possible cancer diagnosis</li> <li>• Give patients incremental information as the diagnostic process unfolds</li> <li>• Inform patients of the reasons for diagnostic tests</li> <li>• When diagnosis is confirmed, warn patient before communicating the diagnosis</li> <li>• Warn patient by reminding patient of earlier conversations of possible diagnosis</li> <li>• Confirm diagnosis only once patient has been warned</li> <li>• Maintain hope</li> </ul>
Engage in patient-centred communication	<ul style="list-style-type: none"> <li>• Build a relationship with the Zulu patient</li> <li>• Spend time with the patient</li> <li>• Offer the patient support</li> <li>• Demonstrate a personal interest in the patient</li> <li>• Assess and address patient needs, fears and concerns, and coping</li> <li>• Respond to patient questions about the diagnosis</li> <li>• Manage denial</li> </ul>
Engage in culture-centred communication	<ul style="list-style-type: none"> <li>• Take responsibility for improving communication</li> <li>• Include some basic isiZulu phrases in conversations</li> <li>• Demonstrate an understanding of Zulu cultural health beliefs</li> <li>• Reassure patients that their diagnosis is not due to punishment or bewitchment</li> <li>• Demonstrate a genuine interest in patients' culture</li> <li>• Ask patients questions about culture, religion, their understanding of their condition</li> <li>• Offer patients the best care possible regardless of language discordance</li> </ul>
Facilitate understanding of the diagnosis using visual aids	<ul style="list-style-type: none"> <li>• Use images, pictures and information brochures</li> </ul>

<b>Diagnosis</b>	
Facilitate understanding by using the stages of cancer	<ul style="list-style-type: none"> <li>• Educate patients regarding their stage of the disease</li> <li>• Educate patients about the effects of cancer in every stage</li> </ul>
Facilitate understanding of the diagnosis using metaphors	<ul style="list-style-type: none"> <li>• Use metaphors to explain concepts like cells, organs, tumours and metastases</li> <li>• Use patient-initiated metaphors</li> </ul>
Check patient understanding	<ul style="list-style-type: none"> <li>• Repeat information several times</li> <li>• Check what patients remember from previous explanations</li> </ul>
Address language barriers:	<ul style="list-style-type: none"> <li>• Use language that patients can understand</li> <li>• Avoid using medical jargon</li> <li>• Use professional or experienced translators</li> </ul>
Instil hope through MDT involvement	<ul style="list-style-type: none"> <li>• Reassure patients of continued involvement of the multidisciplinary team</li> <li>• Differentiate the different problems that would be addressed</li> <li>• Explain how the different problems would be addressed</li> <li>• Maintain hope regardless of disease stage</li> </ul>
<b>Treatment</b>	
Communicating about treatment options	<ul style="list-style-type: none"> <li>• Inform patients about surgical options</li> <li>• Inform patients about chemotherapy</li> </ul>
Process suggestions when communicating treatment options	<ul style="list-style-type: none"> <li>• Delay providing treatment information until staging investigations are completed</li> <li>• Inform patients about the prognostic consequences of not treating the tumour, e.g. metastases, shortened life-span</li> <li>• Balance hope and honesty</li> <li>• Ensure patient understanding</li> <li>• Explore and manage patients' emotions associated with amputation and chemotherapy</li> </ul>
Strategies for responding to cultural factors associated with amputation	<ul style="list-style-type: none"> <li>• Timing the treatment discussion</li> <li>• Introduce patients to veteran patients that have had amputation</li> <li>• Manage refusal of amputation by ensuring continuity of care and mobilising support</li> </ul>
Strategies for responding to cultural and health beliefs that affect treatment	<ul style="list-style-type: none"> <li>• Initiate discussions about cultural requirements in order to fast track decision-making</li> <li>• Encourage patients to engage in their cultural traditions</li> <li>• Encourage patients to follow Western and traditional</li> </ul>

	<p>approaches</p> <ul style="list-style-type: none"> <li>• Liaise with family and cultural decision-makers where possible</li> <li>• Do not make assumptions based on culture and race</li> <li>• Take responsibility for learning about the Zulu culture</li> <li>• Include traditional healers in patient care</li> </ul>
<b>Prognosis</b>	
Assess patient emotions and knowledge	
Provide patients with realistic prognostic information	<ul style="list-style-type: none"> <li>• Inform patients about the prognostic consequences of not treating the osteosarcoma</li> <li>• Inform patients about treatment limitations</li> <li>• Inform patients that they have metastases</li> <li>• Inform patients about a poor prognosis</li> </ul>
Use a staged approach	
Normalise death	
Do not specify a time frame	

Table 3: Complicating factors in communicating with Zulu patients

<p>Patient factors</p>	<ul style="list-style-type: none"> <li>• Cultural health beliefs about cancer as punishment; caused by bewitchment; resulting in a poor prognosis</li> <li>• Cultural health beliefs about amputation</li> <li>• isiZulu word for cancer is associated with poor prognosis</li> <li>• Lack of clarity regarding how much patients understand about the diagnosis</li> <li>• Patients understand consequences of the diagnosis and not the actual diagnosis</li> <li>• Lack of clarity regarding words in Zulu for the diagnosis of osteosarcoma</li> <li>• Patient and family preference for traditional healing</li> <li>• The need for consultation with elders and family members before treatment decision-making</li> <li>• Patient nondisclosure of traditional beliefs to healthcare providers</li> <li>• Patients' tendency to withdraw when poor prognosis is communicated</li> <li>• Patients not asking about prognosis</li> </ul>
<p>Healthcare provider factors</p>	<ul style="list-style-type: none"> <li>• Lack of training</li> <li>• Perceived lack of competence</li> <li>• Tendency to use medical jargon</li> <li>• Role expectations regarding who communicates about prognosis</li> <li>• Varied perspectives regarding whether patients should be informed about poor prognoses</li> <li>• Timing the prognosis discussion in light of patients' preferences to go home to discuss treatment options</li> </ul>
<p>Organisational factors</p>	<ul style="list-style-type: none"> <li>• Disjointed MDT functioning</li> <li>• Resource constraints <ul style="list-style-type: none"> <li>attendance and scheduling of MDT forums</li> <li>lack of access to professional translators</li> <li>nursing time constraints</li> </ul> </li> </ul>

Our research with Zulu patients diagnosed with osteosarcoma revealed that these patients had extensive understanding of the diagnosis of osteosarcoma, diagnostic procedures, the treatment options applicable to treating osteosarcoma and the side-effects of chemotherapy. Their perceptions and emotional responses with regard to diagnosis and treatment of osteosarcoma varied. Importantly, healthcare providers should note that receiving information had a positive influence on patients' perceptions of and emotional responses to the diagnosis. Patients also reported negative views of chemotherapy and negative emotional responses to its side-effects. As with diagnosis information, receiving sufficient information regarding chemotherapy and its side-effects may also assist with patient adjustment especially as patients highlighted a lack of information pertaining to the side-effects of chemotherapy. A significant contribution of Chapter six is embedded in Zulu patients' descriptions of their cultural and health beliefs and practices. Specific rituals that are performed to ensure successful outcome of medical procedures, to cleanse patients from bad luck and to address the issue of witchcraft were outlined. Consultation with a reputable traditional healer was flagged as an important cultural practice. However, patients varied in their adherence to traditional belief systems, participation in rituals and the extent to which they deferred decision-making to the family thus emphasising the need for a patient-centred approach to medicine which takes the patient's needs and preferences into account, and allows for differences among patients with the same diagnosis and/or from the same ethnic group.<sup>8,9</sup> The interviews with Zulu patients produced eight themes. These are briefly outlined in Table 4.

Table 4: Themes from the Patient Interviews

<b>Themes</b>	<b>Sub-themes</b>
The Zulu patient's account of how the diagnosis was communicated	<ul style="list-style-type: none"> <li>• Informed about diagnostic testing</li> <li>• Given factual information about osteosarcoma</li> <li>• Informed about metastases and recurrence</li> <li>• Emotional well-being and privacy prioritised</li> </ul>
The Zulu patient's account of how treatment options were communicated	<ul style="list-style-type: none"> <li>• Treatment communication prioritised thus communicating urgency</li> <li>• Given factual information about surgical treatment options and chemotherapy</li> <li>• Informed that disease would metastasise without surgical intervention and chemotherapy</li> <li>• Advised that further treatment would be required if metastases were detected</li> </ul>
The Zulu patient's account of how prognosis was communicated	<ul style="list-style-type: none"> <li>• Explained in terms of the threat of recurrence and metastases</li> <li>• Informed that disease would metastasise if left untreated</li> <li>• Informed about recurrence despite treatment</li> <li>• Need for follow ups and diagnostic testing reiterated</li> </ul>
The Zulu patient's understanding of the information provided	<ul style="list-style-type: none"> <li>• Could relay detailed information about the diagnosis of osteosarcoma, the role of diagnostic tests, the concept of metastases and the implications thereof</li> <li>• Had knowledge of the surgical options and the reason why amputations were performed above the affected area</li> <li>• Knew about oral and intravenous chemotherapy and side-effects</li> </ul>
The Zulu patient's perception of the diagnosis and treatment options	<ul style="list-style-type: none"> <li>• Perceptions about diagnosis varied from catastrophic to realistic</li> <li>• Perceptions about treatment varied from catastrophic to being seen as a means of cure</li> </ul>
Zulu patients' emotions regarding the diagnosis and treatment options	<ul style="list-style-type: none"> <li>• Diagnosis - Sadness and the fear of being judged, pitied or excluded</li> <li>• Patients with no understanding of the diagnosis reacted neutrally</li> <li>• Receiving information improved emotions pertaining to diagnosis for those that responded negatively</li> </ul>

Themes	Sub-themes
	<ul style="list-style-type: none"> <li>• Treatment - loss of hope and feeling traumatised</li> <li>• When treatment was seen as a means of excising the cancer – responses were positive</li> </ul>
Zulu patients' experience of the communication process	<ul style="list-style-type: none"> <li>• Satisfied with content and process of information provision</li> <li>• Wanted more information on side-effects of chemotherapy</li> <li>• Positive emotional outcomes of hope and adjustment to diagnosis resulting from the communication</li> <li>• Reported that healthcare providers had taken a genuine interest in them</li> </ul>
Cultural aspects for consideration when treating Zulu patients	<ul style="list-style-type: none"> <li>• Described their cultural and health beliefs and practices</li> <li>• Described the role of consultation with elders, ancestors and traditional healers in decision-making</li> <li>• Varied in adherence to traditional belief systems, participation in rituals and the extent to which decision-making was deferred to the family</li> <li>• Proposed combining Western and traditional belief systems</li> </ul>

The evidence-based practice guideline (Chapter 7) which was the overall aim of this research project was developed based on the findings from the integrative literature review and the studies conducted with the healthcare providers and the Zulu patients. These three sources of evidence facilitated the development of a guideline that presents generic requirements and recommendations for culturally competent communication, and denotes specific strategies for communicating diagnosis, treatment, and prognosis to Zulu patients diagnosed with osteosarcoma. The evidence-based practice guideline also explicates areas that require further research and refinement. Table 5 provides a brief overview of the recommendations proposed in the evidence-based practice guideline.

Table 5: Brief Overview of the Guideline Recommendations

<b>Generic requirements for culturally competent communication</b>	
Healthcare provider awareness	<ul style="list-style-type: none"> <li>• Develop contextual awareness</li> <li>• Develop self-awareness</li> <li>• Develop interpersonal awareness</li> <li>• Develop awareness of cultural expectations in the healthcare setting</li> </ul>
Healthcare provider knowledge	<ul style="list-style-type: none"> <li>• Acquire knowledge of broader contextual factors</li> <li>• Acquire context specific knowledge</li> <li>• Acquire self-knowledge</li> <li>• Acquire knowledge of the patient's culture</li> </ul>
Healthcare provider skills	<ul style="list-style-type: none"> <li>• Acquire and apply cross-cultural communication skills</li> <li>• Ensure patient understanding</li> <li>• Manage differences in the patient-provider encounter</li> <li>• Build the patient-provider relationship</li> <li>• Conduct a comprehensive patient assessment</li> <li>• Accommodate the patients' family</li> <li>• Instil and maintain hope regardless of the disease stage</li> </ul>
Healthcare provider attitudes	<ul style="list-style-type: none"> <li>• Take responsibility for cultural aspects of health and illness</li> <li>• Take responsibility for combating discrimination in healthcare settings</li> <li>• Take responsibility for learning about the Zulu culture</li> <li>• Be willing to learn from patients</li> <li>• Be open to change and growth</li> <li>• Be culturally sensitive</li> <li>• Be willing to listen</li> <li>• Develop and demonstrate respect for cultural diversity, for the patient's culture and their cultural values</li> <li>• Demonstrate respect for patients' spiritual and religious beliefs</li> <li>• Develop an appreciation of different health belief systems</li> <li>• Be willing to explore culture with individual patients</li> <li>• Validate different cultures</li> <li>• Engage in continual self-examination and self-reflection to examine one's own values and assumptions</li> <li>• Be willing to adjust behaviours and attitudes</li> <li>• Reflect on own interaction with cultural groups in the clinical</li> </ul>

	setting
Culturally competent healthcare systems	<ul style="list-style-type: none"> <li>• Cultivate the characteristics of culturally competent healthcare systems</li> <li>• Strategies employed by culturally competent healthcare systems</li> </ul>
<b>Recommended strategies for communicating the diagnosis, treatment and prognosis of osteosarcoma</b>	
Recommended strategies for communicating the diagnosis of osteosarcoma to Zulu patients	<ul style="list-style-type: none"> <li>• Provide patients with factual information</li> <li>• Set the stage for truth-telling</li> <li>• Engage in patient-centred communication</li> <li>• Engage in culture-centred communication</li> <li>• Facilitate understanding of the diagnosis</li> </ul>
Recommended strategies for communicating the treatment of osteosarcoma to Zulu patients	<ul style="list-style-type: none"> <li>• Provide patients with factual information</li> <li>• Follow a specific process when discussing treatment</li> <li>• Strategies for responding to cultural factors associated with amputation</li> <li>• Strategies for responding to cultural and health beliefs that affect treatment</li> </ul>
Recommended strategies for communicating prognostic information pertaining to osteosarcoma with Zulu patients	<ul style="list-style-type: none"> <li>• Assess patient emotions and knowledge</li> <li>• Inform patients of the prognostic consequences of not treating the osteosarcoma</li> <li>• Inform patients of treatment limitations</li> <li>• Inform patients regarding metastases and treatment limitations result from the metastases</li> <li>• Inform patients of poor prognoses</li> <li>• Use a staged approach when patients have non-metastatic or minimally metastasised disease</li> </ul>

## 8.6 Original Contributions

There is very limited research available on culturally competent patient-provider communication in our South African context where multiculturalism and discordant medical encounters abound. This study breaks ground and alerts to the magnitude of research that is required in cross-cultural clinical settings, especially in the South African context. Most research and protocols for communicating about cancer are generic and have not been developed in the African context. Although these protocols are useful, research resulting in recommendations for managing the unique challenges encountered in cross-cultural clinical cancer settings has not been conducted. Our evidence-based

practice guideline (Chapter 7) therefore makes an original contribution to the body of knowledge as it is the first of its kind for the South African context. It not only provides recommendations on generic requirements for culturally competent patient-provider communication, but also explicates specific strategies and recommendations for communicating about the diagnosis, treatment, and prognosis of osteosarcoma to the Zulu patient. Furthermore, each of the objectives that lead to the development of this guideline yielded unique findings. The integrative literature review (Chapter 2), which was conducted to gather existing evidence, was the first of its kind and synthesised how to deliver culturally competent patient-provider communication to cancer patients. The focus groups with healthcare providers allowed access to rich narratives about communication of diagnosis, treatment and prognosis with Zulu patients diagnosed with osteosarcoma. Although an extensive literature exists on communicating the diagnosis of cancer to patients, this research uncovered unique strategies for communicating diagnosis which were not previously noted in the literature (Chapter 3).<sup>10-13</sup> These strategies included actively introducing cultural narratives when communicating with patients in order to demonstrate knowledge of and openness to patients' cultural practices and beliefs; facilitating patient understanding of diagnosis and metastases by explaining the stages of cancer to patients; introducing a unique metaphor not previously described in literature thereby encouraging the discovery of metaphors that may work in a specific context; checking what patients remembered and understood from previous explanations given in order to identify patient misperceptions and denial; and instilling a relational hope that was not necessarily associated with cure but reassured patients of the MDT's continued involvement throughout the disease process (Chapter 3). Interestingly, although healthcare providers reported competency concerns and lack of training with regard to communication of sensitive information to patients, they still reported on methods of communicating diagnosis and prognosis that are confirmed in the literature (Chapters 3 and 5). Healthcare providers in this study therefore demonstrated innovation and relied on experiential knowledge to guide their communication with Zulu patients. Furthermore given that the literature on discussing treatment options in the cancer context is limited, our research revealed content and process suggestions regarding the treatment discussion pertaining to osteosarcoma (Chapter 4).<sup>12,14</sup> Importantly, our research also provided insight into Zulu cultural and health beliefs regarding cancer (Chapter 3) and cultural practices related to the treatment option of amputation (Chapters 4 and 6). The patient interviews revealed rich data on the rituals and decision-making processes inherent in Zulu cultural hierarchical structures but also demonstrated how these processes have evolved (Chapter 6). Our research also provided access to Zulu patients' emotional responses to and perceptions of diagnosis and treatment of osteosarcoma. This study further provided an opportunity to correlate Zulu patients' descriptions of how the diagnosis, treatment and prognosis were communicated (Chapter 6), with healthcare providers' accounts (Chapters 3, 4 and 5). Although there are strong correlations between Zulu patients' and healthcare providers' accounts of the communication of these various aspects, healthcare providers provided a richer account of the prognosis discussion (Chapter 5). Furthermore, delivers another first

in that provides insights into contrasting perceptions between providers and patients regarding the treatment option of amputation (Chapter 6).

### **8.7 Strengths of the Study**

The strengths of this study are reflected in the actions taken to ensure scientific rigour and ethical research practice across all four objectives. With regard to the integrative literature review, an established approach was used to conduct the review.<sup>6</sup> In addition, an independent reviewer experienced in the integrative literature review methodology verified the inclusion and exclusion of records, independently appraised the documents, and verified the data extraction and content analysis of the data extracted from the included documents. Guba's Model of Trustworthiness was used as a guide to ensure the scientific rigour of the studies conducted with the healthcare providers and the Zulu patients.<sup>15</sup> The focus group interviews were conducted by an experienced qualitative researcher in order to minimise bias as the primary investigator is part of the MDT that treats Zulu patients diagnosed with osteosarcoma. The focus group interviewer and the primary investigator independently coded the data which was further reviewed by two qualitative research experts. The data analysis process was extensive and iterative. The interviews with Zulu patients were conducted by Zulu fieldworkers and the consent form was also available in isiZulu. Patients were encouraged to express themselves freely and also advised that they could withdraw from the study at any time without any recourse. The data from these interviews were translated into English and back translated to ensure accuracy of translation. Data was independently coded by a qualitative research expert and themes were then agreed upon. The research designs and methodologies for all the studies were described in detail and allows for replicability of the work. The evidence-based practice guideline was developed using the AGREE II Instrument which provides a framework for assessing the quality of guidelines; provides a methodological strategy for the development of guidelines; and informs what information should be reported in guidelines and in what manner.<sup>16</sup> The guideline development process was supervised by experienced researchers and clinicians and reviewed by five expert panel reviewers.

From an experiential perspective, focus group participants reflected that they experienced the focus group participation as transformative. They were able to reflect on their current practice, share challenges with and learn from fellow participants. In addition, experiential knowledge was revealed as healthcare providers demonstrated innovation by using a number of strategies which were confirmed in the literature; this despite their concerns about competency and lack of training. In addition, the researchers developed an awareness of cultural competency deficits during the writing process. An example - phrases like '*strategies for managing challenges associated with amputation*' were changed to '*strategies for managing factors associated with amputation*'. There was a realisation that cultural practices and beliefs cannot be perceived as 'challenges' if there is to be an

appropriate culturally competent response to patients. Following this realisation, the researchers further appreciated that patients' cultural beliefs and practices are not to be 'managed' as something separate to who they are. The sub-theme eventually read as follows: *Strategies for responding to cultural factors associated with amputation.*

### **8.8 Limitations of the Study**

The evidence derived from the integrative literature review was mostly low level evidence (Level VII) and hence the results had to be interpreted with caution.<sup>17</sup> Furthermore, most of the studies that met the inclusion criteria for inclusion in the integrative literature review were international. With regard to the focus groups with healthcare providers, all those that were eligible to participate were approached but some MDT members were not available at the time of data collection. Our use of discipline specific focus groups likely enhanced our ability to explore issues common to each professional group, however it may have restricted our opportunity to assess the inter-professional functioning of MDT members, which is likely an important factor given the high pressure environment in which the study was conducted. Our results may have been enhanced had other qualitative data gathering techniques been used to complement the focus group interviews. With regard to the patient interviews, patients were asked to provide retrospective accounts of their experiences and the interviews were conducted at one point in time and not as the disease process unfolded. Furthermore, the challenges experienced with regard to locating participants limited the size of the sample. Although a Zulu interviewer ensured that patients could express themselves in their own language, the interviewer already knew what patients meant with regard to some of the cultural aspects that were discussed and hence these were not further explored. Zulu patients' accounts of how prognosis was communicated were limited in comparison to the healthcare providers' descriptions of the prognosis communication.

### **8.9 Practice Implications**

The obvious contribution to clinical practice resulting from this work is represented in the evidence-based practice guideline (Chapter 7). However, each of the manuscripts, if read in isolation, make a significant contribution to practice. The integrative literature review (Chapter 2) provided a detailed table of the requirements for culturally competent patient-provider communication. Chapter three presented strategies for communicating about diagnosis in cross-cultural settings. Chapter four had content and process suggestions for discussing treatment in situations where intervention is urgent. This chapter also discussed some strategies for responding to cultural beliefs and practices in a culturally competent manner. Specific strategies for communicating about prognosis to patients were outlined in Chapter five. In chapter six, patients alluded to ways in which practice in cross-cultural settings can be improved. They emphasised providing adequate information to patients and recommended that cultural beliefs and practices be respected and integrated into the management of

cancer. Variability in patients' experience of their illness and in the extent to which they engage in cultural practices is an important consideration in cross-cultural clinical settings. Healthcare providers should be careful not to stereotype based on pre-existing knowledge of a cultural group or of how individuals are expected to respond to a life-threatening illness.

## **8.10 Future Directions**

### 8.10.1 Research

Although all areas can be expanded on, one of the main areas that require further research is that of prognosis. The study findings from the focus group interviews with healthcare providers offered information on what is being said to patients and why it is said however; further investigation is required to explore how it is said. Contextual research on patients' preferences for prognostic communication emerged as a prominent area for future research. This need was further emphasised when prognosis descriptions in the patient study were limited. Furthermore, although patients reported that they were satisfied with how the diagnosis, treatment and prognosis was communicated to them, research exploring patients' experience of the proposed communication strategies that emerged from the focus group interviews could assist in refining these strategies. Deviations from Western research findings and the discovery of unique strategies and challenges emphasized the need for studies further exploring patient-provider communication in cross-cultural encounters. Methodologically, the use of a range of qualitative data gathering techniques may enhance research findings. The guideline has not been piloted with the target group as this task was beyond the scope of the current research study. However, implementing the guideline and conducting research to investigate its effectiveness will facilitate further development of the guideline.

### 8.10.2 Training

The healthcare providers consistently mentioned a lack of training and resultant competency concerns with regard to sharing sensitive information with patients. Including detailed modules on communication and cultural competency should be considered an essential part of training healthcare providers. Communication has far-reaching consequences with regard to patient satisfaction, negotiation of treatment goals, adherence and health outcomes in general. However, training can also be implemented at health facility level as is proposed with regard to implementing the evidence-based practice guideline that was developed as part of this study.

### 8.10.3 Policy

This research study focused on clinical cultural competence but alluded to the importance of culturally competent healthcare systems in providing competent communication to patients across cultural boundaries. Culturally competent healthcare systems develop and implement policies to support effective cross-cultural communication.<sup>18,19</sup> Lack of access to resources like professional

interpreters and patient navigators require policy intervention at a systems level. Healthcare systems where culturally discordant patient-provider encounters abound can contribute significantly to culturally competent practice through policy development and implementation that support culturally competent practices. This evidence-based practice guideline includes a section on culturally competent healthcare systems and can be used as a guide when developing policies.

## **8.11 Chapter Conclusion**

This chapter synthesised the main findings of this research project and explicated the original contributions of the work. The strengths and weaknesses of the study were also explained. The chapter concludes with a discussion of the practice implications derived from our findings and future directions for culturally competent communication in culturally discordant clinical settings in terms of research, training and policy.

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## **Appendices**

Appendix A: The Study Protocol

Appendix B: Letter to the CEO of the Hospital

Appendix C: Information Sheet and Informed Consent: Patients

Appendix D: Information Sheet and Informed Consent: Providers

Appendix E: Patient Demographic Information and Interview Schedule

Appendix F: Provider Demographic Information and Interview Schedule

Appendix G: Ethical Approvals

Appendix H: Evidence-Based Practice Guideline

Appendix I: AGREE II Items

## **Appendix A: The Study Protocol**

University of KwaZulu-Natal  
College of Health Sciences  
School of Clinical Medicine

**Culturally competent patient-provider communication with Zulu patients diagnosed with Osteosarcoma**

**Degree: PhD**

**Principal Investigator: Otilia Brown**  
**Student number: 214585792**

Address: Grey's Hospital, Pietermaritzburg

Tel: 0338973135

Cell: 0721944916

E-mail: [ottiliabrown1978@gmail.com](mailto:ottiliabrown1978@gmail.com)

**Supervisor: Dr. Colleen Aldous**  
**E-mail address: [aldousc@ukzn.ac.za](mailto:aldousc@ukzn.ac.za)**

**Co-supervisor: Dr. Len Marais**  
**E-mail address: [Leonard.Marais@kznhealth.gov.za](mailto:Leonard.Marais@kznhealth.gov.za)**

**Co-supervisor: Prof Dalena van Rooyen**  
**E-mail address: [Dalena.VanRooyen@nmmu.ac.za](mailto:Dalena.VanRooyen@nmmu.ac.za)**

## EXECUTIVE SUMMARY

### Statement of purpose

The purpose of this study is to develop evidence-based practice guidelines for culturally competent patient-provider communication with Zulu patients regarding the diagnosis, treatment and prognosis of osteosarcoma. The study will be conducted with osteosarcoma patients and health professionals treating osteosarcoma at a tertiary hospital in KwaZulu-Natal. An integrative literature review detailing the existing evidence for culturally competent patient-provider communication will also be conducted. At this stage in the research culturally competent patient-provider communication will generally be defined as the demonstration of an understanding of the importance of social and cultural influences on patients' health beliefs and behaviours and a consideration of how these factors interact at multiple levels of the health care delivery system.

This study aims to make a contribution to the improved management of Zulu patients diagnosed with osteosarcoma. Clinical observations have highlighted various cultural dimensions that play a significant role in the management of these patients. Zulu patients diagnosed with osteosarcoma often present for treatment when the disease has already started metastasising. Furthermore patients often demonstrate a misunderstanding of the nature of the disease both before and after medical counselling. Treatment options may include limb ablation or limb salvage which presents patients with various cultural considerations. Culturally appropriate management of the Zulu patient with osteosarcoma could significantly reduce time between diagnosis and treatment. The aggressive nature of osteosarcoma combined with late presentation for treatment increases the risk of metastases which may then result in palliative as opposed to curative management of patients.

The researcher aims to explore Zulu patients' understanding of the diagnosis, treatment and prognosis of osteosarcoma. Patients previously treated for osteosarcoma at the Tumour, Sepsis and Reconstruction Unit at a tertiary institution in Kwa-Zulu Natal will be approached to explore their understanding of the disease and to gain insight into their experience at the hospital during diagnosis and treatment. An exploratory descriptive study of the current approach that health professionals take when discussing cancer, its treatment as well as prognosis with patients will be conducted. Patients will be interviewed by Zulu-speaking fieldworkers with the aid of semi-structured interview guides and focus group interviews will be conducted with providers. A literature review will guide the construction of these interview schedules. Knowledge gained from analysing data gathered from patients and health professionals in conjunction with an integrative literature review will be used to develop an evidence based practice guideline for culturally competent patient-provider communication with regard to osteosarcoma. It is envisaged that the guideline could be adapted for use with other cancers.

The project outputs will include three to five peer-reviewed publications and presentations at medical and psychology conferences. Furthermore, a concise report of the findings and the manner in which culturally competent patient-provider communication can be implemented in South African healthcare settings will be submitted to the Department of Health HOD and KZN Health Research and Knowledge Management. The findings will also be distributed to medical training institutions.

The main purpose of the project is to improve patient care by providing patients with culturally competent patient-provider communication in order for patients to assimilate their diagnosis and make decisions regarding treatment. In addition, the findings of this project can be used to influence training of healthcare professionals in the South African context.

# THE PROTOCOL

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## **1. DEFINING THE RESEARCH PROBLEM**

According to Steyn and Muller<sup>1</sup> cancer, which is classified as a non-communicable disease, is on the increase in South Africa despite advances in treatment, and prevention and education efforts. Non-communicable diseases (NCDs) are the leading cause of mortality globally, causing more deaths than all other causes combined. According to the World Health Organisation (WHO),<sup>2</sup> 36 million people died from NCDs in 2008 globally with 21 percent of these deaths being attributed to cancers. Globally, deaths due to NCDs are projected to increase by 17% over the next ten years, but the greatest increase (24%) is expected in the African region. By 2030 it is estimated that NCDs will contribute to 75% of global deaths.<sup>3</sup> According to the WHO, NCDs accounted for 29% of deaths in South Africa in 2008, with seven percent of these deaths being attributed to cancers. Statistics South Africa attributed 40% of deaths to NCDs in 2008, with seven percent being attributed to cancer.<sup>4</sup>

Osteosarcoma is the most frequent primary solid malignancy of bone and is derived from primitive mesenchymal cells. Untreated osteosarcomas can result in local and/or metastatic disease progression.<sup>5</sup> Despite advances in treatment of osteosarcoma,<sup>6</sup> survival is dependent on diagnosis prior to progression beyond localised disease. The majority of patients presenting at the study site already have locally advanced or metastatic disease thus negatively affecting treatment options and outcomes for survival.<sup>7</sup> Treatment options include chemotherapy and surgery which can include either limb salvage or limb ablation.<sup>8</sup> Limb salvage is not an option in patients with advanced local disease, meaning that limb ablation, often more as a palliative and quality of life measure is the only surgical option at the study site.

A further complication in addition to the late presentation of these patients for treatment is that Zulu patients often require extensive familial and ancestral consultations and rituals before agreeing to limb ablation. This further delay in treatment, given the aggressive nature of osteosarcoma can further complicate quality of life and survival outcomes. It then becomes important for providers to communicate an understanding of these cultural beliefs while at the same time communicating the urgency of the matter and the negative effect on survival. This requires the skill of breaking bad news in a culturally sensitive manner that engenders cooperation in the patient while allowing them the opportunity to fulfil their cultural obligations. The purpose of this research is therefore the development of an evidence-based practice guideline for culturally competent patient-provider communication in order to maximise treatment outcomes for Zulu patients diagnosed with osteosarcoma.

## **2. LITERATURE OVERVIEW AND MOTIVATION**

The primary motivation for undertaking this research stems from observations in clinical practice and research findings<sup>7</sup> indicating that Zulu patients diagnosed with osteosarcoma often present for treatment when the disease has already started metastasising. Furthermore, the principal investigator and members of the multidisciplinary team have noted that these patients tend to demonstrate a misunderstanding of the nature of the disease both before and after medical counselling. Osteosarcoma is the most frequent primary solid malignancy of bone and is derived from primitive mesenchymal cells. Untreated osteosarcomas can result in local and/or metastatic disease progression.<sup>5</sup> It has been noted in the literature that patients present late for treatment partly due to misdiagnosis at community health centres (CHCs) or district hospitals,<sup>7</sup> while practice indicated that late presentation may be partially due Zulu patients' preference to exhaust all traditional healing options before seeking Western medical assistance. A delay in diagnosis and treatment significantly affects prognosis. This study therefore intends to gain insight into Zulu patients' conceptualisations of

the illness, understand current provider practices with regard to interacting with Zulu patients about osteosarcoma and gather existing evidence from the literature by conducting an integrative literature review in order to develop evidence-based practice guidelines for culturally competent patient-provider communication. The ultimate aim is the reduction of health disparities and the maximisation of health outcomes for Zulu patients diagnosed with osteosarcoma. The background for this study is now explicated.

### **Communicating with cancer patients**

A detailed literature search delivered no literature specifically pertaining to osteosarcoma and patient-provider communication hence this section will focus on cancer in general. Communicating with cancer patients presents with unique challenges due to the life-threatening nature of the illness. Despite advances in treatment, cancer is still commonly associated with negative emotions such as fear and anxiety.<sup>9</sup> Discussing the diagnosis, treatment and prognosis of cancer with patients is commonly viewed as breaking bad news.<sup>10</sup> Bad news is typically defined as information that negatively and seriously affects an individual's view of their future.<sup>11</sup> Healthcare providers generally regard breaking bad news and coping with the emotional responses of patients resulting from such news as stressful.<sup>12</sup> Providers' communication skills have a significant effect on both the patient and the provider. The link between effective patient-provider communication and patient satisfaction, compliance with treatment, quality of life and health outcomes is well-documented.<sup>12,14,15</sup> Effective patient-provider communication can also positively influence provider burnout, professional satisfaction and decrease litigation.<sup>16</sup> For the cancer patient, effective provider communication can affect the psychological well-being of patients receiving a cancer diagnosis and increase their sense of control and involvement in their care.<sup>17</sup> However this benefit is reciprocal as providers are equally dependent on good patient-provider communication in order to facilitate diagnostic and treatment processes.<sup>15,18</sup>

Barrett<sup>19</sup> defined good patient-provider communication as patients understanding the health information and treatment recommendations that are explained to them, and feeling comfortable enough to ask for clarification when they do not understand something. According to Raynor<sup>20</sup>, increasing individuals' ability to understand and participate in their healthcare is an international health priority. The ability to understand health information is known as health literacy. Individuals' health literacy can greatly affect health outcomes and mortality.<sup>21</sup> Patients with inadequate health literacy may not understand medical jargon regarding diagnosis, treatment and prognosis.<sup>22</sup> Furthermore, the literature suggests that there is great variability in the degree of patient understanding of their cancer, that patients tend to incorrectly state the extent of the disease and the goal of treatment, and tend to overestimate prognosis.<sup>23,24,25</sup> It is essential that cancer patients understand their diagnosis and various treatment options available to them in order to facilitate informed decision-making. However, studies have indicated that patients have preferences with regard to the manner in which bad news is delivered to them.

#### **Patient information needs**

A review of patients' preferences with regard to receiving bad news revealed that four components, namely setting, manner of communicating bad news, what and how much information is provided and emotional support are considered important factors.<sup>10</sup> For example, Parker *et al*<sup>26</sup> found in their study that provider expertise and receiving diagnostic and treatment information was most important to patients followed by the need for support from providers when receiving information. On the other hand, Hack<sup>25</sup> reported that communication outcomes are enhanced when providers primarily attend to

the emotional needs of patients when breaking bad news. Patients' information needs may also be influenced by their attitudes to cancer and their strategies for coping. Patients may want information at diagnosis but this may vary across the disease trajectory depending on factors such as their faith in their doctor's expertise, their need to maintain hope by avoiding detailed knowledge, and an awareness of limited resources which results in an acceptance that limited information is a given.<sup>27</sup> Patient preferences have also been associated with demographic variables such as age, gender, and educational level with younger patients, female patients and more highly educated patients consistently expressing a need to receive detailed information as well as emotional support.<sup>10</sup>

The cancer literature on providing information to patients tends to encourage truth-telling in breaking bad news to patients. The literature alerts to the fact that while diagnoses are often readily disclosed as providers are ethically and legally expected to do so, disclosure of prognostic information occurs less often.<sup>28</sup> A systematic review of the literature by Hagerty *et al*<sup>29</sup> revealed that there is little available evidence regarding the best method for communicating prognosis or of the impact of prognostic information on patient outcomes. A number of difficulties arise when communicating prognosis to patients such as level of truth-telling regarding survival estimates especially in the case of patients with poor prognoses.<sup>30</sup> A study by Hagerty *et al*<sup>31</sup> of metastatic cancer patients found that most of these patients wanted detailed prognostic information but preferred to negotiate the extent, format, and timing of the information they received while another study found that patients with advanced disease desired less information about their illness.<sup>32</sup> A South African study revealed that 78.5 percent of that study sample wanted to be informed of prognosis with regard to their specific cancer.<sup>33</sup> Culture has also been shown to complicate information provision when discussing prognosis with patients.<sup>34</sup> This aspect is discussed in more detail in the following section. The variability in research findings are a clear indication that providers need to assess patient information needs and be wary of adopting a generic approach to addressing these needs.<sup>25,30,32</sup>

### **Culture and patient-provider communication**

Culture can be defined as “a system of beliefs, values, rules and customs that is shared by a group and is used to interpret experiences and direct patterns of behavior”.<sup>35</sup> Culture is an important consideration in clinical care as it plays a significant role in how patients' health-related values, beliefs and behaviours are shaped.<sup>35</sup> Cultural diversity in South Africa essentially means that patients are more often than not treated by a provider from a different culture to their own. Managing cancer in a multicultural context further complicates the patient-provider relationship.<sup>36</sup> An example where this is evident is related to patient information needs across the disease trajectory. Some cultures such as Italian, Chinese and Japanese cultures may value nondisclosure of diagnosis and of a terminal prognosis<sup>37,38</sup> whereas cultures derived from a Western philosophy tend to value fully informing patients.<sup>39</sup> It is important for providers to become aware of cultural preferences regarding cancer disclosure. This would include understanding of patient preferences for involving the family in decision-making, the use of nonverbal communication and the psychosocial impact of terminologies used.<sup>37,40</sup> Understanding all these facets does by no means intimate that providers can adopt a ‘one size fits all’ approach when addressing individuals from certain cultural backgrounds, as various factors such as acculturation and urbanisation may influence individual preferences and communication needs.<sup>40</sup>

Culture affects patients' and communities' interaction with cancer, patients' approaches to its treatment and trust in providers and institutions. Similarly culture has been shown to affect individual professionals' and institutions' approach to minority patients.<sup>41</sup> While it is well-known that cultural factors are crucial to diagnosis, treatment and efficient management of illness, overemphasis on

culturally categorising patients may result in stereotyping.<sup>42</sup> The other side of this pertains to providers' awareness of their own cultural backgrounds and contexts<sup>43</sup> and of how this interacts with that of the patient as well as the culture of medicine.<sup>42,43</sup> Disparities in healthcare particularly those related to race and ethnicity, are well-documented and significantly influence access to and optimal use of healthcare services.<sup>14,44,45,46,47</sup> However, the concept of culture, as earlier defined, is not solely associated with race and ethnicity.<sup>48</sup> It is noteworthy that South Africa presents with disparities in health and wealth that are amongst the highest in the world.<sup>47</sup> Despite post-apartheid South Africa awarding high priority to health equity<sup>49</sup>, a 2008 study by Kon and Lackan<sup>46</sup> showed that Black and Coloured South Africans were still underserved and disadvantaged especially with regard to health care. Health disparities have multiple complex causes including genetics, poverty, access to health care, behaviour, and environmental factors.<sup>45</sup> The complex interactions of political and racially motivated policies such as the South African apartheid policies<sup>47</sup> as well as globally documented causes of health disparities such as low socioeconomic status, unemployment, lower levels of education, and occupations and living environments that expose individuals to hazards<sup>50</sup> require intervention at many levels in order to address the problem of health disparities. While large scale interventions on the policy and institutional level may be required, literature increasingly points to the role that cultural competence can play in reducing health disparities.<sup>14,41,44,51</sup>

“Cultural competence in health care entails: understanding the importance of social and cultural influences on patients' health beliefs and behaviors; considering how these factors interact at multiple levels of the health care delivery system; and, finally, devising interventions that take these issues into account to assure quality health care delivery to diverse patient populations.”<sup>51</sup> Surbonne<sup>52</sup> described cultural competence in medicine as complex and multi-layered. Cultural competence can be achieved via organisational, structural and clinical cultural competence interventions.<sup>51</sup> On the organisational level this refers to ensuring that the leadership and staff compliment of a health care delivery system is diverse and representative of its patient population. Structural cultural competence interventions address structural processes that limit access to quality health care while clinical cultural competence interventions address provider knowledge of the interaction between sociocultural factors and health beliefs and behaviours as well as equipping providers with the skills to manage these culturally complex interactions. The overall aim of this research is the development of an evidence-based practice guideline for culturally competent patient-provider communication with regard to osteosarcoma diagnosis, treatment and prognosis. This study will address the issue of culturally competent patient-provider communication and therefore falls in the domain of clinical cultural competence interventions. Culturally competent patient-provider communication can be defined as the ability to communicate with awareness and knowledge of how sociocultural factors contribute to healthcare disparities, how cultural factors influence health beliefs and behaviours and in addition possessing the skills to manage these factors effectively in cross-cultural patient-provider contexts.<sup>53</sup>

Inherent in the concept of cultural competence as described above is the patient-centered approach to medicine. This approach, in line with the concept of cultural competence, expects that the provider takes the patient's needs and preferences into account<sup>54</sup> and allows for differences among patients with the same diagnosis and/or from the same ethnic group.<sup>48</sup> Bensing<sup>54</sup> argues that patient-centered medicine and evidence-based medicine are on opposite ends of the continuum as the former purports humanism and a biopsychosocial approach and the latter denotes positivism and a biomedical approach. Both paradigms are deemed relevant and essential, and on close inspection are possible at the same time despite them housing completely opposite paradigms. Bensing<sup>54</sup> described communication as absolutely key to patient-centered medicine and intimated that strengthening the evidence base of patient-centered medicine lies in conducting communication research. This author

firstly calls for research that links communication to health outcomes and also appeals for greater efforts in synthesising the evidence in order to develop evidence-based practice guidelines and protocols. This study is in line with the latter plea with specific emphasis being placed on culturally competent patient-provider communication with Zulu patients diagnosed with osteosarcoma. While much has been written on the concept of cultural competence, there is a lack of agreement with regard to how to best implement this at the individual patient care level.<sup>48</sup> The aim is that a review of the evidence from existing literature as well as the generation of new evidence by means of semi-structured interviews with patients and providers will result in an evidence-based practice guideline for this specific population group. The approach taken in this research therefore reflects the general consensus in the literature that evidence-based practice typically includes three key components namely, research-based evidence available from the literature, clinical expertise and patient preferences.<sup>55,56</sup>

The interviews with providers will take an interprofessional approach and diverge from the cited literature where providers are mostly medical professionals. Interprofessionalism promotes collaborative practice that is organised around the needs of the population being served and includes multiple health workers from different professional backgrounds working together with patients, families, carers and communities in order to deliver the highest quality of care.<sup>57</sup> The team consists of consultants and registrars from the Department of Orthopaedics at the institution where the study will be conducted, registered nurses, a social worker, a clinical psychologist, dieticians, a physiotherapist and an occupational therapist. Community organisations and individuals are co-opted as the need arises depending on patient needs. All members of the team will be approached for participation in the research.

The benefits and purpose of evidence-based practice guidelines are to summarise and synthesise knowledge and innovations in medicine; to reduce variation in practice; and to improve quality of patient care.<sup>58,59</sup> Evidence-based practice guidelines are developed in a transparent and structured manner and reviews, rates and synthesises a large body of evidence resulting in a series of recommendations that can improve provider practice and patient outcomes simultaneously. This study will conclude with the developed guidelines being reviewed by an expert panel consisting of people with expertise in clinical content; experts in literature reviews or guideline development, or both; and potential users of the guideline.<sup>60</sup>

### 3. AIM AND OBJECTIVES

The overall aim of the study is to develop an evidence-based practice guideline for culturally competent patient-provider communication with Zulu patients with regard to osteosarcoma diagnosis, treatment and prognosis. This aim will be achieved by meeting the following 4 objectives:

**Objective 1:** A study of patients previously treated for osteosarcoma to explore patient understanding of the osteosarcoma diagnosis, its treatment and prognosis, and patient experience of the patient-provider relationship throughout the illness experience. Qualitative semi-structured interviews will be conducted to gather this information. Trained fieldworkers will conduct the interviews in Zulu.

**Objective 2:** An exploratory descriptive study of the approach taken by health professionals when discussing osteosarcoma, its treatment and prognosis with patients. A focus group interview guide consisting of semi-structured questions will be used to elicit information regarding the process and content that multidisciplinary team members follow when discussing osteosarcoma with Zulu patients.

**Objective 3:** An integrative literature review which will be used to address the review question. Some topics that will arise may include: skills for cultural competence; models of cultural competence which have been used in cancer settings; evidence-based practice guidelines for cultural competence in healthcare settings. The integrative literature review allows for the inclusion of studies with diverse methodologies. It comprises a number of key stages: problem identification, literature search data evaluation, data analysis and presentation<sup>61</sup>.

**Objective 4:** Develop an evidence-based practice guideline for culturally competent patient-provider communication with osteosarcoma patients based on the evidence collected.

## **4. METHODS**

### **4.1. STUDY DESIGN FOR RESEARCH OBJECTIVE 1**

Objective 1: Qualitative semi-structured interviews will be used to explore and describe previously diagnosed patients' understanding of the causes, symptoms, diagnosis and treatment of osteosarcoma, and patient experience of the patient-provider relationship throughout the illness experience. A qualitative exploratory descriptive study design will be used to achieve this objective.

#### **SETTING**

The Tumour, Sepsis and Reconstruction (TSR) Unit at Grey's Hospital has a patient register of osteosarcoma patients treated at Grey's Hospital. Permission to access this register will be obtained from the head of the TSR Unit. Patients will either be accessed when they attend their outpatient appointments at the Orthopaedic Clinic or when they attend the Oncology Clinic for chemotherapy. Patients that have completed their treatment could be telephonically invited to attend an interview at Grey's Hospital. Their transport costs will be covered. Written informed consent will be obtained from each participant prior to commencement of the data collection (Appendix C).

#### **PARTICIPANT SELECTION**

Nonprobability purposive sampling will be used to select Zulu participants diagnosed with osteosarcoma from patient register held by the TSR Unit. The researcher will not include newly diagnosed patients in the study. Only outpatients that are receiving follow-up at Orthopaedic Outpatients or chemotherapy and follow-up at the Oncology Department will be included in the study.

#### **MEASUREMENTS**

A semi-structured interview schedule (Appendix E) guided by a literature review will be used to assess patients' knowledge of the causes, symptoms, diagnosis and treatment of osteosarcoma. This schedule will also consist of a biographical section to be completed by the interviewer before commencement of the interview in order to gather biographical data about the patients. Patients' experience of the patient-provider relationship will also be explored. Trained fieldworkers will conduct the interviews in Zulu. The interview schedule will be piloted on at least one Zulu speaking osteosarcoma patient before administering it to the rest of the participants. If no changes are made based on this pilot, the data will be included in the study for analysis. Interviews will be audio taped and transcribed, then translated into English and analysed from the English translations.

## DATA ANALYSIS

Data from the semi-structured interviews will be analysed using thematic analysis. Thematic analysis is a data analysis technique commonly employed in qualitative research for identifying, analysing, and reporting patterns within data<sup>62</sup>. There are a number of steps in thematic analysis:

1. The first step involves familiarising yourself with your data. This entails transcribing data (if necessary), reading and rereading the data, and noting down initial ideas.
2. The researcher then generates initial codes. This requires the researcher to code interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. The researcher then searches for themes by collating codes into potential themes, gathering all data relevant to each potential theme.
4. Themes are then reviewed and refined by checking the collated extracts for each theme and observing whether they form a coherent pattern (Level 1). Extracts that do not fit into a theme could be an indication that the theme is problematic and needs to be reworked or could mean that a new theme(s) has to be created for those extracts or alternatively that extracts have to be discarded. A thematic map is now generated of the themes and the researcher can move to Level 2 of this step which involves considering the validity of individual themes in relation to the entire data set.
5. Themes are then defined and named. This entails ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells thereby generating clear definitions and names for each theme.
6. The researcher then selects vivid, compelling extract examples, relating these back to the research question and literature and presenting a discussion of the findings.<sup>62</sup>

Guba's model of trustworthiness will be utilized<sup>63</sup> in order to verify the accuracy of the findings. This model addresses four issues of trustworthiness, namely credibility, transferability, dependability and confirmability. In addressing credibility, the researcher and fieldworkers will use interviewing techniques and skills such as probing, reframing, clarifying and summarizing. The same semi-structured interview schedule and procedures for interviewing will be used with each patient. Confidentiality of information gathered and anonymity in reporting of the results of the findings will be guaranteed and explained to participants during the consent process. Member checking will be used to verify the findings. Transferability will be addressed by saving the data analysis documents that will be used to generate the findings. Furthermore, the detailed descriptions of the research procedures followed will be documented. Dependability will be ensured by keeping a dense description of the research methods, processes and steps followed. Confirmability will be ensured by using an independent coder and member checking.

## SAMPLE SIZE

Sample size will be determined by employing the guiding principle of the concept of saturation point which refers to the point at which no new information or themes are observed in the data.<sup>64</sup> While there are no specific rules regarding sample size in qualitative research,<sup>65</sup> it generally relies on smaller numbers. An experiment by Guest *et al*<sup>64</sup> revealed that saturation could be achieved as early as 6 interviews, with 12 interviews being sufficient according to their study on saturation. However, sample homogeneity, good quality data and specific rigorous inquiries are essential to limit the number of participants required for the study.<sup>64</sup> This objective requires a homogenous Zulu patient population previously diagnosed with osteosarcoma. The objective is clearly specified and the interview questions will be piloted before they are administered to the participants.

## **4.2. STUDY DESIGN FOR RESEARCH OBJECTIVE 2**

**Objective 2:** Qualitative semi-structured interviews will be used to explore and describe the process and content of providers discussing osteosarcoma, its treatment and prognosis with patients.

A qualitative exploratory descriptive study design will be used to achieve this objective. Focus groups will be organised in order to extract the process and content of discussing the diagnosis, treatment and prognosis of osteosarcoma with patients. The focus group is a qualitative research method for eliciting descriptive data from population subgroups.<sup>66</sup>

### **SETTING**

Health professionals in the Orthopaedic registrar programme and consultants are usually involved in sharing news regarding diagnosis, treatment and prognosis of osteosarcoma with patients. Registrars rotating through the TSR Unit and consultants will be interviewed. At the tertiary institution where the research will be conducted, a team approach is used to manage patients diagnosed with osteosarcoma. This team comprises dieticians, an occupational therapist, a physiotherapist, a social worker, a clinical psychologist, and registered nurses working in the outpatient orthopaedic clinic and the orthopaedic wards where these patients are admitted.

### **PARTICIPANT SELECTION**

All members of the team as outlined in the previous section will be approached to participate in the study. Nonprobability purposive sampling will therefore be used to achieve this objective of the study. Inclusion criteria stipulates that participants must be members of the multidisciplinary team managing Zulu patients diagnosed with osteosarcoma and orthopaedic registrars that have worked or are working in the TSR Unit. Three separate focus groups consisting of the orthopaedic consultants and registrars, the nurses and allied health professionals respectively will be convened in order to collect the data for this objective.

### **MEASUREMENTS**

A focus group interview guide (Appendix F) consisting of semi-structured questions will be used to elicit information regarding the process and content that multidisciplinary team members follow when discussing osteosarcoma with Zulu patients. The schedule will attempt to elicit whether there is a particular sequence of information provision that is followed and the nature of the content of information shared. The schedule will also attempt to tap into considerations of the team members regarding type of information shared. The interview schedule will be piloted on a colleague to ensure that the appropriate data is being elicited for the purpose of the study.

### **DATA ANALYSIS**

Data from the focus groups will be analysed using thematic analysis as discussed in section 4.1. Guba's model of trustworthiness will be utilized<sup>63</sup> in order to verify the accuracy of the findings. Additional considerations in ensuring trustworthiness of the data gathering and data analysis refer to the fact that the researcher will conduct the focus groups. The process of bracketing<sup>67</sup> will be used whereby the researcher is aware of own preconceived ideas and outcomes for the study as well as knowledge gained while reading in preparation for the study, and uses this awareness to minimise potential deleterious effects of these preconceptions on the research process.

### **SAMPLE SIZE**

Usually eight to 12 members comprise a focus group.<sup>66</sup> The researcher plans to constitute three focus groups: the orthopaedic consultants and registrars; the nursing staff comprising of registered nurses

working in the orthopaedic wards and orthopaedic outpatient department; and allied health professionals comprising of those individuals assigned to working with patients diagnosed with osteosarcoma. Saturation may not be possible with this objective as there are a limited number of individuals that can be invited to participate in the focus groups. All members of the team may not be interested in participating.

### **4.3. STUDY DESIGN FOR RESEARCH OBJECTIVE 3**

**Objective 3:** An integrative literature review will be conducted to gather evidence from previous research. The integrative literature review allows for the inclusion of studies with diverse methodologies.<sup>61</sup> It comprises a number of key stages: problem identification, literature search, data evaluation, data analysis and presentation as outlined in Whittemore and Knaf.<sup>61</sup>

#### **4.3.1 Problem identification**

The review question was formulated using the PICO guide.<sup>68</sup> This guide divides each question into four components:

**Patients/population:** which patients or population of patients are we interested in? How can they be best described? Are there subgroups that need to be considered?

**Intervention:** which intervention, treatment or approach should be used?

**Comparison:** what is/are the main alternative/s to compare with the intervention? This is the optional component in the PICO question as the researcher may only look at the intervention without exploring alternatives, and in some cases, there may not be an alternative.

**Outcome:** what is really important for the patient? Which outcomes should be considered: intermediate or short-term measures; mortality; morbidity and treatment complications; rates of relapse; late morbidity and readmission; return to work, physical and social functioning and other measures such as quality of life; general health status; costs?<sup>68</sup>

The review question therefore based on PICO:

**Patients/population** – The patient population focused on in this study are Zulu patients diagnosed with osteosarcoma.

**Intervention** – The proposed intervention is culturally competent patient-provider communication.

**Comparison** – no comparison or alternative intervention is proposed.

**Outcome** – Improving treatment outcomes, either curative or palliative depending on disease stage at first presentation to the institution.

**Review Question:** Among Zulu patients diagnosed with osteosarcoma, does culturally competent patient-provider communication improve treatment outcomes?

#### **4.3.2 Literature search**

A detailed search strategy will be devised to address the problem. Examples of databases that will be searched: EBSCOhost will be used to search across databases including MEDLINE, PsychINFO, CINAHL; PubMed; BioMed Central; Sabinet Online; National Guideline Clearinghouse website; Google Scholar; cancer, research and governmental organisations' websites. Keywords used will

include but are not limited to: cultural competence, cancer, osteosarcoma, patient-provider communication.

Inclusion criteria: All literature relevant to the problem will be included; English and Afrikaans data will be included as the principal investigator is fluent in these languages; all literature from 1982 when the term cultural competence first appeared in the literature<sup>69</sup> will be included. Grey literature which has been defined as "(t)hat which is produced on all levels of government, academics, business and industry in print and electronic formats, but which is not controlled by commercial publishers"<sup>70</sup> will also be included in the integrative literature review. Literature that duplicates information and that pertains to cultural competence in disciplines other than healthcare will be excluded from the review.

### 4.3.3 Data evaluation

Once all the relevant literature has been identified, evidence evaluation will be done by using a hierarchy system in order to rate the evidence. There are different levels of evidence depending on the type of study. The literature presents with a plethora of systems for evaluating evidence. The system proposed by Muir Gray<sup>71</sup> is well-documented in the evidence-based practice literature and will be used to evaluate the quantitative evidence. This rating system is presented in Table 1.

Table 1: Levels of Evidence for Quantitative Research

Level I (strongest evidence)	Strong evidence from at least one systematic review of multiple well-designed randomised controlled trials.
Level II	Strong evidence from at least one properly designed randomised controlled trial of appropriate size.
Level III	Evidence from well-designed trials such as pseudo-randomised or non-randomised trials, cohort studies, time series or matched case-controlled studies
Level IV	Evidence from well-designed non-experimental studies from more than one centre or research group or from case reports.
Level V	Opinions of respected authorities, based on clinical evidence, descriptive studies or reports of expert committees.

A hierarchy of evidence for assessing qualitative health research as proposed by Daly *et al*<sup>72</sup> is outlined in Table 2.

Table 2: A Qualitative Hierarchy of Evidence-for-Practice

Level I (strongest evidence)	Generalisable studies
Level II	Conceptual studies
Level III	Descriptive studies
Level IV	Single case studies

Once evidence has been identified and graded as previously described, critical appraisal tools will be used to “carefully and systematically examin(e) research to judge its trustworthiness, and its value and relevance in a particular context”.<sup>73</sup>

Systematic reviews will be appraised using the AMSTAR which is a measurement tool to assess the methodological quality of the review.<sup>74</sup> This has been shown to have good face and content validity.

Quantitative research will be appraised using the HCPRDU Evaluation Tool for Quantitative Studies developed by Long *et al*<sup>75</sup> under the auspices of the Health Care Practice Research and Development Unit (HCPRDU) at the University of Salford, UK in a study regarding the feasibility of undertaking systematic reviews in social care.

Qualitative research will be appraised using the Critical Appraisal Skills Programme (CASP) tool for assessing qualitative research. According to the National Collaborating Centre for Methods and Tools (NCCMT),<sup>76</sup> CASP helped to develop an evidence-based approach in health and social care, working with local, national and international groups. CASP tools assess internal validity, the results of the study and the relevance of the results to practice.<sup>76</sup>

Mixed method studies will be appraised using the HCPRDU Evaluation Tool for Mixed Method Studies developed by Long *et al*<sup>75</sup> under the auspices of the Health Care Practice Research and Development Unit (HCPRDU) at the University of Salford, UK in a study regarding the feasibility of undertaking systematic reviews in social care.

The grey literature will be critically appraised using the AACODS (Authority, Accuracy, Coverage, Objectivity, Date, Significance) checklist.<sup>77</sup> This checklist has the flexibility to be applied to the widest range of resources.

Evidence-based practice guidelines for cultural competency in health settings will be appraised using the AGREE II tool. The AGREE II tool was developed by an international team of guideline developers and researchers known as the Appraisal of Guidelines, Research and Evaluation (AGREE) Collaboration and assesses the methodological rigour of how a clinical practice guideline was developed.<sup>78,79</sup>

To ensure the rigour of the literature search and data evaluation stages of the integrative literature review process, an independent reviewer will be used to minimise bias in selection of studies and to ensure that critical appraisal tools are accurately applied.<sup>80</sup>

#### **4.3.4 Data analysis**

The goals of this stage are a thorough and unbiased interpretation of primary sources as well as an innovative synthesis of the evidence.<sup>61</sup> The process starts with data reduction and extraction. The reviewer has to decide on a classification system for managing the data from diverse methodologies. For the purposes of this research, type of evidence will be used to initially classify the data. Other subgroups may emerge depending on the data collected. The next step in data reduction involves extracting and coding data thereby organising it into a manageable framework. Data extraction is guided by the specific questions asked of the data. This is followed by data display which involves converting the extracted data from individual sources into a display that assembles the data from multiple primary sources around particular variables or subgroups. Data display leads to the next step in data analysis namely data comparison. The reviewer now has to compare the data in order to identify patterns, themes and/or relationships. This is followed by drawing conclusions and verifying the data. Patterns and processes are identified and conflicting evidence is highlighted and discussed. Typically a table is used so that systematic comparison of primary sources on specific aspects is possible.<sup>61</sup>

#### **4.3.5 Data presentation**

The data will be presented in the form of tables. This will be followed by a discussion of the main findings. Implications for practice, future research and policy development<sup>61</sup> will be highlighted.

#### **4.4. STUDY DESIGN FOR RESEARCH OBJECTIVE 4**

**Objective 4:** Develop an evidence-based practice guideline for culturally competent patient provider communication with Zulu patients diagnosed with osteosarcoma based on the evidence collected from the semi-structured interviews with patients, the focus groups with providers and the integrative literature review. The guideline will be externally reviewed by an expert panel which will consist of people with expertise in clinical content; experts in literature reviews or guideline development, or both; and potential users of the guideline.<sup>60</sup>

There are a number of approaches to evidence-based clinical practice guideline development. Turner *et al*<sup>81</sup> reviewed six evidence-based clinical practice guideline handbooks and advised that given the considerable agreement between these approaches, limited available resources should be spent on collating approaches as opposed to updating individual approaches. The NICE (National Institute for Health and Clinical Excellence) approach fared very well in this review. Similarly in a review of nineteen handbooks<sup>82</sup>, the NICE handbook scored the best. This approach is therefore proposed as a guide for developing the evidence-based practice guideline for this research. The steps suggested in the NICE handbook are briefly outlined and applied to this study.<sup>68</sup>

##### **4.4.1 Topic Selection**

The topic for the guideline has already been selected based on clinical observations and literature findings (first step in guideline development).

##### **4.4.2 Scoping the clinical practice guideline (CPG)**

This step includes the following key tasks: considering the guideline remit; undertaking a preliminary literature search; identifying key aspects of care to be included; and reviewing the scope after consultation.<sup>68</sup> All of these tasks have already been performed in the compilation of this protocol. However, reviewing the scope of the CPG is an ongoing process in consultation with the supervisors for this study.

##### **4.4.3 Formulating the Guideline Development Group (GDG):**

The GDG typically includes health professionals, those familiar with issues affecting patients and carers, and technical experts. Zulu patients diagnosed with osteosarcoma will be interviewed in order to achieve the first objective of this study. Health professionals involved with managing Zulu patients diagnosed with osteosarcoma will be interviewed to gather data for the second objective of this study. These health professionals will also be involved in member checking of that data and will be invited to comment on the CPG. Furthermore, the supervisors of this research as well as technical experts on integrative literature reviews and CPG development will be consulted throughout the course of this research.

##### **4.4.4 Formulate the clinical questions**

This was achieved by using the PICO guide.<sup>68</sup> The clinical question for this guideline is: Among Zulu patients diagnosed with osteosarcoma, does culturally competent patient-provider communication improve treatment outcomes?

#### 4.4.5 Identify the evidence

A search strategy will be developed and relevant databases will be searched using the inclusion and exclusion criteria set for the evidence. This step in the process will basically involve objectives 1 to 3 previously discussed.

#### 4.4.6 Review and grade the evidence

The levels of evidence for quantitative and qualitative evidence as well as the critical appraisal tools outlined in section 4.3.3 of Objective 3 will apply to this step of the CPG development.

#### 4.4.7 Create guideline recommendations

Once the evidence has been critically appraised, the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) system<sup>83</sup> will be used to grade the quality of the evidence and the strength of guideline recommendations. This step also includes prioritising guidelines for implementation.<sup>68</sup> The GRADE system is outlined in Table 3.

Table 3: GRADE grades of evidence

High	Further research is very unlikely to change our confidence in the estimate of effect.
Moderate	Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate
Low	Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate
Very low	Any estimate of effect is very uncertain.

#### 4.4.8 Preparing the guideline

This is an iterative process that involves at least two drafts of the guideline as well as review by the GDG or an expert panel convened for the purpose of reviewing the guideline before the final document is compiled.<sup>68</sup> The expert panel will consist of people with expertise in clinical content; experts in literature reviews or guideline development, or both; and potential users of the guideline.<sup>60</sup> The AGREE II tool will also be used to evaluate the methodological rigour of how the clinical practice guideline was developed.<sup>78,79</sup>

The NICE guideline development process does not include the step of evidence transfer<sup>56</sup> which relates to the careful development of strategies that involves packaging knowledge for the transfer to individual health professionals, health facilities and health systems globally by means of journals, other publications, electronic media, education and training and decision support systems. The information has to be understandable and actionable, be context specific taking into account the recipients' needs; and delivered in a cost-effective manner.<sup>56</sup> The data gathered will be published in peer reviewed journals for each of the objectives. Information will further be disseminated to the Department of Health KZN HOD in the form of a report. The information will also be made available to the professionals that participated in this study in order to improve practice with the study population. The hospital management and KZN Health Research and Knowledge Management will also receive a copy of the findings.

### 5. ETHICAL CONSIDERATIONS

A number of ethical considerations are important for the purposes of this study.

### Informed consent

Informed consent will be ensured in this study in that each prospective participant will receive an information sheet (Appendices C and D) explaining the nature and purpose of the study, who the researcher is, the issues of confidentiality and anonymity and a contact number should any questions arise. The researcher/fieldworkers collecting the data will provide a detailed explanation of the research, its duration and the issues of confidentiality and anonymity. The information sheet also contains the contact details for BREC should the participants be concerned that ethical violations occurred during the research. The information sheet for patients will be translated into Zulu once BREC approval has been obtained.

### Coercion

Participants will be informed of their right to voluntary consent and their right to withdraw from the study at any time. Patient participants will also be reassured that their decision regarding participation in the study will not affect their access to healthcare in any way.

### Privacy and confidentiality

The fact that the researcher will personally contact and make appointments with participants means that the participants will not be anonymous to the researcher. However, anonymity and confidentiality in reporting of the findings will be maintained at all times.

### Risk of Harm to Patients

Zulu patients diagnosed with osteosarcoma will be approached for participation in the study. Patients will be asked about their illness as well as their experience of the healthcare system. Retelling their stories may evoke negative emotional responses in these patients. Counselling will be provided should patients require this as a result of participating in this study. It should be noted that osteosarcoma patients are referred to the Clinical Psychology Department before final diagnoses are made. These patients therefore receive ongoing psychological intervention from the time of work-up and throughout the treatment process should they agree to this service. In addition, many of these patients are serviced by the Social Work Department as well. The risk of harm noted is therefore minimal but will be taken into account nonetheless.

### Ethics Approval

The study will be submitted for ethics approval to the UKZN Bioethics Research and Ethics Committee (BREC) and permission to conduct the study at the institution will be sought from the CEO of Grey's Hospital (Appendix A) as well as KZN Health Research and Knowledge Management.

## **6. BUDGET**

<b>Item</b>	<b>Cost</b>
Independent Coder	R1000
Transcribers	R1500
Translations	R2000
Fieldworkers	R1200
<b>TOTAL</b>	<b>R5700</b>

## 7. TIME LINES AND PROJECT MANAGEMENT

Task	Date
BREC Approval	January 2015
Data collection from patients	February to June 2015
Data collection from health professionals	February to June 2015
Integrative literature review	January to December 2015
Development of the evidence-based practice guideline	January 2015 to August 2016
Compiling final document	August to December 2016

## 8. CONTRIBUTORS AND AUTHORSHIP

Name	Department	Contribution (to be determined as study progresses)	Author or acknowledgement
Otilia Brown	Internal Medicine		Author
Dr Colleen Aldous	Clinical Medicine		Author
Dr Len Marais	Clinical Medicine		Author
Prof Dalena van Rooyen	NMMU		Author

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## **Appendix B: Letter to the CEO of the Hospital**



health

Department:  
Health  
**PROVINCE OF KWAZULU-NATAL**

**GREY'S HOSPITAL**  
**CLINICAL PSYCHOLOGY DEPARTMENT**  
Private Bag X9001, PIETERMARITZBURG, 3200  
Townbush Road, Chase Valley, PIETERMARITZBURG,  
3201  
Tel.: 033 – 897 3135, Fax: 033 – 345 5278

DATE:

Dear Dr Bilenge

**RE: Permission to Conduct Research at Grey's Hospital**

I would like to request permission to conduct research at Grey's Hospital. The research is for PhD degree purposes but also forms part of my job description and KRAs for EPMDs. The project is entitled: *Culturally competent patient-provider communication as a means of improving health outcomes in Zulu patients diagnosed with osteosarcoma*. The study entails the interviewing of Zulu patients previously diagnosed with osteosarcoma now receiving outpatient treatment. The study will also involve focus group interviews with health professionals involved in the multidisciplinary management of these patients. The research protocol will be submitted to the UKZN Biomedical research Ethics Committee (BREC) for ethics approval and your office will be furnished with the approval number and any correspondence from BREC. KZN Health Research and Knowledge Management will also be approached for permission to conduct the study and your office will once again be furnished with communiqué from this unit. The study will therefore only commence with your permission and once permission has been obtained from the entities as described. A copy of the research protocol is attached.

Please do not hesitate to contact me should you have any queries.

Yours sincerely,

Otilia Brown

Principal Clinical Psychologist

## **Appendix C: Information Sheets and Informed Consent: Patients**

Information Sheets and Informed Consent: Patients (English)

Information Sheets and Informed Consent: Patients (isiZulu)



health

Department:  
Health  
**PROVINCE OF KWAZULU-NATAL**

**GREY'S HOSPITAL**  
**CLINICAL PSYCHOLOGY DEPARTMENT**  
Private Bag X9001, PIETERMARITZBURG, 3200  
Town Bush Road, Chase Valley, PIETERMARITZBURG,  
3201  
Tel.: 033 – 897 3135, Fax: 033 – 345 5278

Date:

Dear Patient

My name is Otilia Brown and I am the principal clinical psychologist in the Clinical Psychology Department at Grey's Hospital. My contact information is as follows:

Email: [Otilia.Brown@kznhealth.gov.za](mailto:Otilia.Brown@kznhealth.gov.za)

Office telephone: 033 897 3135

Pager: 137

I would like to invite you to consider participating in a study that involves research on culturally competent patient-provider communication with Zulu patients diagnosed with osteosarcoma. The aim and purpose of this research is to develop a guideline for health professionals that help them to communicate with patients in such a manner that the patients feel like their cultural background is taken into account. The researcher cannot specify how many participants will be approached at this point because it will depend on the type of information that each participant offers the researcher. A fieldworker will conduct interviews in Zulu. Your interview will be recorded so that it can be written down word for word and translated into English so that the researcher can understand the information. Once the information has been looked at by the researcher, she will approach you again to make sure that she understood correctly what you were trying to convey in the interview. If you choose to participate in the study, you will be contacted on two occasions, first for the interview and secondly when the researcher checks that she understands the information correctly.

You may be asked questions about the time when you were diagnosed with osteosarcoma and this may result in you remembering some unpleasant things linked to that time. The researcher will ensure that you have access to counselling should this be the case. While there may be no direct benefits to you from participating in this study, we hope that the guideline that will be developed in this study will help with successful management of patients diagnosed with osteosarcoma in the future.

This study has been ethically reviewed and approved by the UKZN Biomedical research Ethics Committee (approval number\_\_\_\_\_).

In the event of any problems or concerns/questions you may contact the researcher at 033 897 3135 or the UKZN Biomedical Research Ethics Committee, contact details as follows:

## BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus  
Govan Mbeki Building  
Private Bag X 54001  
Durban  
4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

Email: [PREC@ukzn.ac.za](mailto:PREC@ukzn.ac.za)

Participation in this research is voluntary and you may withdraw participation at any point. In the event of refusal/withdrawal of participation, you will not incur penalty or loss of treatment or other benefit to which you are normally entitled. If you decide that you do not want to participate in the study any longer, inform the fieldworker during the interview process or inform the researcher on 033 897 3135 or on email as listed above.

While you will not be paid for participation in the study, your transport costs to the hospital will be paid if you are being interviewed on a day that you are not at the hospital for other outpatient appointments.

Please note that confidentiality will be maintained at all times. Codes will be used instead of patient names. Recordings will be stored with password protection on an electronic device. The recordings will only be used for the purposes of this research and will only be heard by the researcher, the transcriber and those supervising the study as well as the person that will be double checking that the researcher has analysed the information correctly (independent coder).

---

### CONSENT

I \_\_\_\_\_ have been informed about the study entitled: *Culturally competent patient-provider communication as a means of improving health outcomes for Zulu patients diagnosed with osteosarcoma* by \_\_\_\_\_.

I understand the purpose and procedures of the study.

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any treatment or care that I would usually be entitled to.

I have been informed that I will receive counselling if I experience any negative emotions or reactions as a result of participating in this study.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at 033 897 3135.

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

**BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus  
Govan Mbeki Building  
Private Bag X 54001  
Durban  
4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)

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**Signature of Participant**

---

**Date**

---

**Signature of Witness**  
**(Where applicable)**

---

**Date**

---

**Signature of Translator**  
**(Where applicable)**

---

**Date**



health

Department:  
Health  
**PROVINCE OF KWAZULU-NATAL**

**GREY'S HOSPITAL**  
**CLINICAL PSYCHOLOGY DEPARTMENT**  
Private Bag X9001, PIETERMARITZBURG, 3200  
Town Bush Road, Chase Valley,  
PIETERMARITZBURG, 3201  
Tel.: 033 – 897 3135, Fax: 033 – 345 5278

Usuku:

Ngiyabingelela Mzali

My name is Otilia Brown and I am the principal clinical psychologist in the Clinical Psychology Department at Grey's Hospital. My contact information is as follows:

Email: Otilia.Brown@kznhealth.gov.za

Office telephone: 033 897 3135

Pager: 137

Ngicela ukukumema ukuthi uzibandakanye ocwaningweni oluhlanganisa ukuxhumana komuntu osiza isiguli owaziyo ngamasiko oxhumana neziguli ezingamaZulu ezinesifo somdlavuza (osteosarcoma). Injongo nenhloso yalolu cwaningo ukwakha umhlahlandlela ozosetshenziswa abezempilo ozobasiza ukuxhumana neziguli ngendlela yokuthi iziguli zizizwe ukuthi amasiko azo akanyathelwa noma ayabhekelelwa. Angeke umcwaningi acacise ukuthi bangakhi abazozibandakanya okuzokhulunywa nabo okwamanje ngoba lokhu kuzoncika ohlotsheni lolwazi oluzonikwa ngozibandakanyayo enika umcwaningi. Ozobe eqoqa ulwazi uzoxoxisana nabantu ngesiZulu. Ingxoxo yakho izoqoshwa ukuze ibhalwe phansi igama negama bese ihunyushelwa eSingisini ukuze umcwaningi ezoluqonda ulwazi. Uma ulwazi selubukiwe umcwaningi, uyophinde akucele futhi ukuqinisekisa ukuthi ukuqonde kahle obewuzama ukukudlulisa ngesikhathi sokuxoxisana nozibandakanyayo. Uma ukhetha ukuzibandakanya ocwaningweni, kuyoxhunyanwa nawe kabili, okokuqala kuyobe kungokokuxoxisana bese okwesibili lapho umcwaningi esebheka ukuthi uluqonda kahle ulwazi.

Ungabuzwa imibuzo ngesikhathi kutholakala ukuthi unomdlavuza (osteosarcoma) kanti lokhu kungaba nomphumela wokuthi ukhumbule izinto ezingezinhle ezenzeka ngaleso sikhathi. Umcwaningi uyoqinisekisa ukuthi uyokwazi ukwelulekwa ngokwqengqondo uma lokhu kwenzeka. Nakuba kungeke kubekhona imihlomulo eqondile eza kuwena ngokuzibandakanya kulolu cwaningo, sithemba ukuthi umhlahlandlela oyokwakhiwa kulolu cwaningo uyosiza ukuphathwa ngokunempumelelo iziguli okutholwe ukuthi zinomdlavuza (osteosarcoma) esikhathini esizayo.

Lolu cwaningo selubuyezwe laphinda lagunyazwa yi-UKZN Biomedical research Ethics Committee (Inombolo yokugunyaza\_\_\_\_\_).

Uma kungaba nezinkinga noma okukukhathazayo/imibuzo ungaxhumana nomcwaningi ku-033 897 3135 noma i-UKZN Biomedical Research Ethics Committee, imininingwane yokuxhumana:

## **BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

Email: BREC@ukzn.ac.za

Ukuzibandakanya kulolu cwaningo kungukuvolontiya kanti ungahoxa ekuzibandakanyeni nanoma yingasiphi isikhathi. Uma unqaba ukuzibandakanya noma uhoxa, angeke uhlawuliswe noma ulahlekelwe wukwelashwa okade ukuthola noma eminye imihlomulo okufanele uyithole. Uma ukhetha ukuthi awusafuni ukuzibandakanya ocwaningweni, tshela lowo oqoqa ulwazi ngesikhathi nisaxoxisana noma utshele umcwaningi kule nombolo 033 897 3135 no kwi-email njengoba ibhaliwe ngezansi.

Nakuba ungeke ukhokhelwe ngokuzibandakanya ocwaningweni, izindleko zokugubela kwakho uya esibhedlela ziyokhokhwa uma kuyoxoxiswana nawe ngosuku oluyobe lungakudingi ukuthi uye esibhedlela uyokwenza ezinye izinto.

Sicela uqaphele ukuthi ubumfihlo buyogcinwa ngazo zonke izikhathi. Kuyosetshenziswa amakhodi esikhundleni samagama esiguli. Okuqoshiwe kuyolondolozwa nenombolo eyimfihlo emshinini wezobuchwepheshe (Umuntu onekhodi ozimele).

---

## **UKUVUMA**

Mina \_\_\_\_\_ ngazisiwe ngocwaningo olisihloko sithi: Culturally competent patient-provider communication as a means of improving health outcomes for Zulu patients diagnosed with osteosarcoma by \_\_\_\_\_.

Ngiyayiqonda inhloso kanye nenqubo yocwaningo.

Nginikeziwe ithuba lokuphendula imibuzo ngocwaningo futhi ngathola nezimpendulo ezingiculisayo.

Ngiyasho ukuthi ukuzibandakanya kwami kulolu cwaningo kungukuvolontiya kanti ngingahoxa nanoma yingasiphi isikhathi ngaphandle kokuphazamiseka kokwelashwa kwami noma ukunakekelwa engijwayele ukukuthola.

Ngithseliwe ukuthi ngizothola ukwelulekwa ngokwengqondo uma kwenzeka ngingaphatheki kahle ngokomphefumulo noma okuzokwenzeka ngenxa yokuzibandakanya kulolu cwaningo.

Uma ngiseneminye imibuzo/okungikhathazayo okumayelana nocwaningo, ngiyaqonda ukuthi ngingaxhumana nomcwaningi kule nombolo 033 897 3135.

Uma ngingaba nanoma emiphi imibuzo noma okungikhathazayo ngamalungelo ami njengozibandakanya ocwaningweni, noma uma ngikathazwa ingenye ethile yocwaningo noma abacwaningi ngakho ngingaxhumana ne:

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Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

Email: BREC@ukzn.ac.za

---

**Kusayine ozibandakanyayo**

---

**Usuku**

---

**Kusayine ufakazi**

**(Uma kunesidingo)**

---

**Usuku**

---

**Kusayine umhumushi**

**(Uma kunesidingo)**

---

**Usuku**

## **Appendix D: Information Sheet and Informed Consent: Providers**



health

Department:  
Health  
**PROVINCE OF KWAZULU-NATAL**

**GREY'S HOSPITAL**  
**CLINICAL PSYCHOLOGY DEPARTMENT**  
Private Bag X9001, PIETERMARITZBURG, 3200  
Town Bush Road, Chase Valley, PIETERMARITZBURG,  
3201  
Tel.: 033 – 897 3135, Fax: 033 – 345 5278

Date:

Dear Healthcare Professional

My name is Otilia Brown and I am the principal clinical psychologist in the Clinical Psychology Department at Grey's Hospital. My contact information is as follows:

Email: [Otilia.Brown@kznhealth.gov.za](mailto:Otilia.Brown@kznhealth.gov.za)

Office telephone: 033 897 3135

Pager: 137

I would like to invite you to consider participating in a study that involves research on culturally competent patient-provider communication with Zulu patients diagnosed with osteosarcoma. The aim and purpose of this research is to develop an evidence-based practice guideline for culturally competent patient-provider communication with Zulu patients about osteosarcoma. The researcher aims to conduct three focus groups; one with medical professionals, one with nursing staff and one with allied health professionals. The focus groups will be recorded so that they can be transcribed verbatim. Once the researcher has analysed the transcribed information, she will approach you again to make sure that she understood correctly what you were trying to convey in the interview. If you choose to participate in the study, you will be contacted on two occasions, first for the focus group and secondly when the researcher checks that she understands the information correctly.

While there may be no direct benefits to you from participating in this study, we hope that the guideline that will be developed in this study will facilitate the successful management of patients diagnosed with osteosarcoma in the future.

This study has been ethically reviewed and approved by the UKZN Biomedical research Ethics Committee (approval number\_\_\_\_\_).

In the event of any problems or concerns/questions you may contact the researcher at 033 897 3135 or the UKZN Biomedical Research Ethics Committee, contact details as follows:

#### **BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus  
Govan Mbeki Building  
Private Bag X 54001  
Durban  
4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)

Participation in this research is voluntary and you may withdraw participation at any point without any negative consequence to you. If you decide that you do not want to participate in the study any longer, inform the researcher during the focus group process or inform the researcher on the contact information listed above.

Please note that confidentiality will be maintained at all times. Codes will be used instead of participant names. Recordings will be stored with password protection on an electronic device. The recordings will only be used for the purposes of this research and will only be heard by the researcher, the transcriber, the independent coder and those supervising the study.

---

## CONSENT

I \_\_\_\_\_ have been informed about the study entitled *Culturally competent patient-provider communication as a means of improving health outcomes for Zulu patients diagnosed with osteosarcoma* by \_\_\_\_\_.

I understand the purpose and procedures of the study (add these again if appropriate).

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any treatment or care that I would usually be entitled to.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at 033 897 3135.

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

## BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus  
Govan Mbeki Building  
Private Bag X 54001  
Durban  
4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)

---

**Signature of Participant**

---

**Date**

---

**Signature of Witness**

---

**Date**

**Appendix E: Patient Demographic Information and Interview Schedule (English and isiZulu versions)**



health

Department:  
Health  
PROVINCE OF KWAZULU-NATAL

GREY'S HOSPITAL  
CLINICAL PSYCHOLOGY DEPARTMENT  
Private Bag X9001, PIETERMARITZBURG, 3200  
Town Bush Road, Chase Valley, PIETERMARITZBURG,  
3201  
Tel.: 033 – 897 3135, Fax: 033 – 345 5278

**Patient Demographic Information and Interview Schedule**

**Patient Information**

Code	
Contact number	
Area of residence	
Age	
Gender	<input type="checkbox"/> Female <input type="checkbox"/> Male
Employment status	<input type="checkbox"/> Unemployed <input type="checkbox"/> Self-employed <input type="checkbox"/> Part-time employment <input type="checkbox"/> Employed
Occupation	
Relationship status	<input type="checkbox"/> Married <input type="checkbox"/> Divorced <input type="checkbox"/> Widowed <input type="checkbox"/> Co-habiting <input type="checkbox"/> Single <input type="checkbox"/> In a relationship
Religious affiliation	
Traditional belief system	

### **Interview Schedule**

1. How do you understand the diagnosis of osteosarcoma (cancer)?
2. Can you provide details on how the diagnosis of osteosarcoma was given to you?
3. What is your understanding of how this illness is treated?
4. Can you provide details on how the treatment options were discussed with you?
5. What information did you receive about the course of the condition/ the likely outcome of the condition (prognosis)?
6. What are the cultural considerations that you had to take into account when you heard the diagnosis and had to decide on treatment? Some cues for this question include:
  - a. Consulting the family
  - b. Consulting a traditional healer
  - c. Rituals
  - d. Ancestors
7. A number of different health professionals cared for you when you were diagnosed and treated. Can you give us some indication of what this experience was like for you?
8. Do you have any suggestions on how the health professionals can improve their communication with you?

### **Ishejuli yokuxoxisana nesiguli**

1. Ukuqonda kanjani ukuhlololwa umdlavuza (osteosarcoma/cancer)?
2. Unganikeza imininingwane ukuthi kwenziwa kanjani ukuhlololwa umdlavuza kuwena? (osteosarcoma)
3. Kuthini okwakho ukuqonda ngokwelashelwa lesi sifo?
4. Unganikeza imininingwane ngokuthi kwaxoxiswana kanjani nawe ngezindlela zokwelapha ezikhona?
5. Wathola oluphi ulwazi ngembangela yalesi simo/nanemiphumela yalesi simo? (prognosis).
6. Eziphi izinyathelo mayelana nesiko okwafanele uziqaphele ngesikhathi uzwa ngokutholakala kwesifo kuwena futhi bese ukhetha ngohlobo lokwelashwa? Ezinye zezibonelo zalo mbuzo zihlanganisa lokhu :
  - a. Ukuxhumana nomndeni
  - b. Ukuxhumana nolapha ngesintu
  - c. Imisebenzi efaka isiko
  - d. Amadlozi
7. Izisebenzi zezempilo zikunakekele ngesikhathi kutholwa ukuthi unalesi sifo futhi wanakekelwa. Ungasivezela ukuthi lesi sipiliyoni saba njani kuwena?
8. Kungabe unayo imibono ukuthi izisebenzi zezempilo zingakwenza ngcono kanjani ukuxhumana nawe?

## **Appendix F: Provider Demographic Information and Interview Schedule**



health

Department:  
Health  
**PROVINCE OF KWAZULU-NATAL**

**GREY'S HOSPITAL**  
**CLINICAL PSYCHOLOGY DEPARTMENT**  
Private Bag X9001, PIETERMARITZBURG, 3200  
Town Bush Road, Chase Valley, PIETERMARITZBURG,  
3201  
Tel.: 033 – 897 3135, Fax: 033 – 345 5278

### Provider Demographic Information and Interview Schedule

#### Provider Information

Code	
Contact number	
Age	
Gender	<input type="checkbox"/> Female <input type="checkbox"/> Male
Professional registration category	<input type="checkbox"/> Consultant <input type="checkbox"/> Registrar <input type="checkbox"/> Registered Nurse <input type="checkbox"/> Occupational therapist <input type="checkbox"/> Social Worker <input type="checkbox"/> Dietician <input type="checkbox"/> Physiotherapist
Ethnicity	
Religious affiliation	
Traditional belief system	

#### Interview Schedule

1. How do you go about discussing the diagnosis of osteosarcoma with the Zulu patient?
  - a. Are there specific steps or processes that you follow?
2. How do you usually discuss treatment options with this patient?
3. How do you discuss prognosis with this patient?
4. If you prefer not to discuss prognosis with patients, how do you respond when they ask about it?
5. What role does culture play in your discussions with patients?

## **Appendix G: Ethical approvals**

Ethical Approval from the Biomedical Research Ethics Committee (BREC) at UKZN

Site Approval

KZN Health Research and Knowledge Management Approval



02 July 2015

Ms O Brown (214585792)  
School of Clinical Medicine  
Medical School  
[ottiliabrown1978@gmail.com](mailto:ottiliabrown1978@gmail.com)

BREC reference number: BE051/15

PROTOCOL: Culturally competent patient-provider communication with Zulu patients diagnosed with Osteosarcoma.

Degree: PhD

### EXPEDITED APPLICATION

A sub-committee of the Biomedical Research Ethics Committee has considered and noted your application received on 10 February 2015.

The study was provisionally approved pending appropriate responses to queries raised. Your responses received on 21 May 2015 to queries raised on 20 April 2015 have been noted by a sub-committee of the Biomedical Research Ethics Committee. The conditions have now been met and the study is given full ethics approval.

This approval is valid for one year from **02 July 2015**. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2015), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

The sub-committee's decision will be **RATIFIED** by a full Committee at its meeting taking place on **14 July 2015**.

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely

Professor J Tsoka-Gwegweni  
Chair: Biomedical Research Ethics Committee

---

Biomedical Research Ethics Committee

Professor J Tsoka-Gwegweni (Chair)

Westville Campus, Govan Mbeki Building

Postal Address: Private Bag X54001, Durban 4000

Telephone: +27 (0) 31 260 2486 Facsimile: +27 (0) 31 260 4609 Email: [brec@ukzn.ac.za](mailto:brec@ukzn.ac.za)

Website: <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>

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Health  
PROVINCE OF KWAZULU-NATAL

GREYS HOSPITAL  
OFFICE OF THE CEO  
Private Bag X 9001, Pietermaritzburg, 3200  
Town Bush Road, Chase Valley, Pietermaritzburg, 3201  
Tel.: 033 – 897 3321 Fax.: 033 - 8973398  
www.kznhealth.gov.za

<b>To:</b> Ms. O. Brown Department of Clinical Psychology Grey's Hospital
<b>From:</b> Dr. K. B. Bilenge CEO - Greys Hospital
<b>Date:</b> 11 May 2015
<b>Re:</b> Request for permission to conduct research at Grey's Hospital: <i>Culturally competent patient-provider communication with Zulu patients diagnosed with Osteosarcoma</i>

Dear Ms. Brown

Your request to conduct research at Grey's Hospital refers.

Permission to conduct the above study is hereby granted under the following conditions:

- Your provisional ethics approval and research protocol is assumed to be valid and final ethics approval is a prerequisite for conducting your study at our hospital. Once obtained from BREC, please submit a copy of the full ethics approval;
- You are also required to obtain approval for your study from the Provincial Department of Health KZN Health Research Unit prior to commencing your study at Grey's Hospital. You will find more information on their website: <http://www.kznhealth.gov.za/hrkm.htm>
- Confidentiality of hospital information, including staff and patient medical and/or contact information, must be kept at all times;
- You are to ensure that your data collection process will not interfere with the routine services at the hospital;
- You are to ensure that hospital resources are not used to manage your data collection, e.g. hospital staff collating data; photocopying; telephone; facsimile, etc.;
- Informed consent is to be obtained from all participants in your study, if applicable;
- Policies, guidelines and protocols of the Department of Health and Grey's Hospital must be adhered to at all times;
- Professional attitude and behaviour whilst dealing with research participants must be exhibited;
- The Department of Health, hospital and its staff will not be held responsible for any negative incidents and/or consequences, including injuries and illnesses that may be contracted on site, litigation matters, etc. that may arise as a result of your study or your presence on site;
- You are required to submit to this office a summary of study findings upon completion of your research.

Recommended by:

Dr L. Naidoo  
Senior Manager: Medical Services

Approved by:

Dr/ K. B. Bilenge  
Hospital CEO

uMnyango Wezempilo . Departement van Gesondheid

*Fighting Disease, Fighting Poverty, Giving Hope*

**Brown Ottilia**

---

**From:** NHRD Support (DO NOT REPLY) <nhrd@hst.co.za>  
**Sent:** 20 May 2015 10:50 AM  
**To:** Brown Ottilia  
**Subject:** National Health Research Database: Important Information

Dear Ottilia.

This email confirms that we have received your application (*KZ\_2015RP41\_758*).

The status of your application has changed.

The new status is: "**Approved**".

Please visit the NHRD website to review your application for research.

Regards  
KwaZulu-Natal Health Research Committee

## **Appendix H: Evidence-Based Practice Guideline**

**Culturally competent patient-provider communication with Zulu patients diagnosed with osteosarcoma: An evidence-based practice guideline**

Otilia Brown

MA (Clin Psych)

Affiliation: University of KwaZulu-Natal, School of Clinical Medicine

Address: Grey's Hospital, Clinical Psychology Department, Private Bag X9001, Pietermaritzburg, 3200

Email: [ottiliabrown1978@gmail.com](mailto:ottiliabrown1978@gmail.com) / Otilia.Brown@kznhealth.gov.za

Telephone: +2733 897 3135 / +2772 194 4916

Prof Dalena (RM) van Rooyen

MCur, PhD

Affiliation: Nelson Mandela Metropolitan University, Faculty of Health Sciences

Address: PO Box 77000, Nelson Mandela Metropolitan University, Port Elizabeth, 6031

Prof Colleen Aldous

PhD

Affiliation: University of KwaZulu-Natal, School of Clinical Medicine

Address: Division of Medicine, Third Floor, Medical School, Private Bag 7, Congella, South Africa 4013

Dr Leonard Charles Marais

MBChB, FC (Orth) SA, MMed (Ortho), CIME, PhD

Affiliation: University of KwaZulu-Natal, School of Clinical Medicine

Address: Grey's Hospital, Department of Orthopaedic Surgery, Private Bag X9001, Pietermaritzburg, 3200

## **Guideline Summary**

**Guideline aim:** The aim of this guideline is to present healthcare providers treating Zulu patients diagnosed with osteosarcoma with evidence-based recommendations that can facilitate culturally competent communication regarding the diagnosis, treatment and prognosis of osteosarcoma.

**Methods and materials:** The AGREE II (Appraisal of Guidelines, Research and Evaluation) appraisal instrument was used as a guide for developing the evidence-based practice guideline. An integrative literature review, focus groups with healthcare providers and in-depth interviews with Zulu patients were conducted to gather the evidence for the evidence-based practice guideline. The guideline was reviewed by an expert panel using the AGREE II tool.

**Setting:** This guideline was developed for healthcare providers communicating with adult Zulu patients diagnosed with osteosarcoma. The Zulu people are indigenous and reside in the predominantly rural South African province of KwaZulu-Natal. They speak isiZulu, one of South Africa's 11 official languages. This province has an overall population of 10.9 million (of a total South African population of 54 956 900 million), the majority of which is classified as Zulu. The focus on osteosarcoma resulted from research findings indicating that the majority of patients presenting at the study site already have locally advanced or metastatic disease. The training hospital where this study was conducted is the referral centre for all patients with osteosarcoma from the western half of the province.

**Results:** The guideline specifies generic aspects such as the awareness, knowledge, skills and provider attitudes required for culturally competent communication as well as the type of healthcare system that can support and cultivate such communication. The guideline then details specific recommendations for communicating the diagnosis, treatment and prognosis of osteosarcoma to Zulu patients. Cultural considerations and responses to these factors are described.

**Conclusion:** Healthcare providers will require cultural competence and communication training in order to facilitate the implementation of the guideline. Some of the challenges identified in the focus group interviews are not addressed in this guideline leaving room for further development of the guideline. However, based on the integrative literature review, focus groups interviews with healthcare providers and in-depth interviews with Zulu patients, specific recommendations for culturally competent communication with this patient group regarding the diagnosis, treatment and prognosis of osteosarcoma were formulated. Evidence-based practice can contribute to improving culturally competent communication with cancer patients receiving treatment at culturally discordant healthcare facilities.

## 1. Introduction

Communicating the diagnosis and prognosis of cancer is widely documented as challenging tasks.<sup>1-10</sup> Furthermore, ensuring that patients understand their treatment options is considered good practice.<sup>11</sup> However literature in this regard tends to be limited. Performing these tasks in cross-cultural clinical settings complicates patient-provider communication.<sup>12</sup> Culture plays a significant role in how patients' health-related values, beliefs and behaviours are shaped, and affects how patients and communities approach the diagnosis and treatment of cancer as well as their trust in healthcare providers and institutions.<sup>13,14</sup> Culture also affects professionals' and institutions' approach to minority patients and contributes substantially to disparities in access to healthcare for minority and underprivileged patients.<sup>14,15</sup> An evidence-based practice guideline would contribute significantly to improving culturally competent communication with cancer patients receiving treatment at culturally discordant healthcare facilities.

This guideline was developed for healthcare providers communicating with adult Zulu patients diagnosed with osteosarcoma. The Zulu people are indigenous and reside in the predominantly rural South African province of KwaZulu-Natal (KZN). They speak isiZulu, one of South Africa's 11 official languages. This province has an overall population of 10.9 million (of a total South African population of 54 956 900 million), the majority of which is classified as Zulu.<sup>16</sup> The focus on osteosarcoma resulted from observations in clinical practice of the significant role that cultural factors play in the management of osteosarcoma. In addition, research findings indicated that the majority of patients presenting at the study site already have locally advanced or metastatic disease.<sup>17</sup> While late presentation of these patients for treatment can be partially attributed to misdiagnosis at community health centres or district hospitals,<sup>17</sup> Zulu cultural practices including extensive familial, ancestral and/or traditional healing consultations and rituals before agreeing to certain treatment options may also play a role. Other observations in clinical practice related to delayed presentation included denial and/or underestimation of the seriousness of the condition. Our research with healthcare providers and Zulu patients at the study site confirmed that cultural considerations were paramount when treating Zulu patients diagnosed with osteosarcoma.

Osteosarcoma is the most frequent primary solid malignancy of bone and is derived from primitive mesenchymal cells. Despite advances in treatment, survival is dependent on diagnosis prior to progression beyond localised disease.<sup>18</sup> The late presentation of patients therefore limits treatment options and results in very poor prognosis.<sup>17,19-22</sup> The treatment options are closely related to patients' understanding of their prognosis and the outcomes resulting from various approaches to treatment. Healthcare providers in this setting are therefore expected to simultaneously inform patients of the diagnosis of osteosarcoma, the significant limitations with regard to treatment options, and prognostic considerations in a culturally sensitive manner that engenders cooperation in the patient while

allowing them the opportunity to fulfil their cultural obligations. Healthcare encounters at the study site are largely culturally discordant. This evidence-based practice guideline was therefore developed to provide recommendations for engaging in culturally competent communication with adult Zulu patients regarding the diagnosis, treatment and prognosis of osteosarcoma. The guideline is intended for use among doctors, nurses and allied health professionals communicating with Zulu patients about the diagnosis, treatment and prognosis of osteosarcoma.

## **2. Methods and Materials**

The AGREE II (Appraisal of Guidelines, Research and Evaluation) appraisal instrument was used as a guide for developing the evidence-based practice guideline.<sup>23</sup> The purpose of the AGREE II Instrument is to provide a framework for assessing the quality of guidelines; provide a methodological strategy for the development of guidelines; and inform what information should be reported in guidelines and in what manner.<sup>24</sup> The original AGREE appraisal instrument was thoroughly investigated and modified to establish the AGREE II tool as the revised standard for guideline development, reporting and evaluation.<sup>25,26</sup> The AGREE II is a 23 item tool comprising six domains. Domain five, applicability, pertains to the likely barriers and facilitators to implementation, strategies to improve uptake, and resource implications of applying the guideline. This domain also assesses whether the guideline presents monitoring and/or auditing criteria. This domain was beyond the scope of this guideline development process.

### **2.1 Comments from the Expert Panel Reviewers**

An expert panel was selected to review the guideline and did not participate in developing the guideline. The AGREE II manual specifies that guidelines should be assessed by at least two reviewers but that four is preferable in order to increase the reliability of the assessment.<sup>23</sup> Five reviewers agreed to appraise the guideline. The expert panel comprised of two nursing professors with extensive methodological knowledge, one of whom conducts research in KZN; one social work professor with methodological as well as field knowledge, having previously worked in public health in the province of KZN; one medical professor involved in training medical professionals in KZN; and one content expert – a clinical psychologist that had previously worked at the study site and had extensive knowledge of Zulu patients and the oncology environment. The AGREE II tool was used to review the guideline. Reviewers could rate each item according to a 7-point scale with response options ranging from strongly disagree to strongly agree. The scores for each domain were calculated as is described in the AGREE II manual.<sup>23</sup> The reviewer comments are now discussed according to the five domains of the AGREE II instrument that were used in the development of this guideline.

### ***2.1.1 Scope and Purpose***

This domain is concerned with the overall aim of the guideline, the review question, and the target population. The guideline reviewers either agreed or strongly agreed that the aim of the guideline, the review question and the target population were clearly described. One of the reviewers suggested that the review question be improved in the following manner: ‘How is culturally competent patient-provider communication best delivered *by healthcare providers* to adult Zulu patients diagnosed with osteosarcoma?’ It was proposed that the phrase ‘by healthcare providers’ be included. The review question was adapted accordingly. The domain score for this section was 92%.

### ***2.1.2 Stakeholder Involvement***

This domain focuses on the extent to which the guideline was developed by the appropriate stakeholders and represents the views of its intended users. The guideline reviewers’ scores ranged from neutral to strongly agree for this domain. One of the reviewers stated that the credentials of the guideline developer should be specified. The credentials of the developer have been included in section 2.2.2. One of the reviewers suggested that it be indicated whether the interview questions used to access the views and preferences of the target population addressed recommendations that were included in the guideline. This has been addressed in section 2.2.3.1.3. Three of the reviewers commented on the number of patients interviewed, one of whom enquired whether other audits or surveys had been done. The number of patients interviewed is a limitation of this guideline and is discussed in section 2.2.3.1.3 and 4.2. Two of the reviewers indicated that the target users of the guideline are clearly described but they requested more detailed information in this regard. A more detailed description of the target users is presented in 2.2.2. One of the reviewers suggested that specific recommendations are aligned to specific healthcare providers. The scope of the current study did not allow for healthcare provider specific recommendations hence this suggestion could be considered when further developing this guideline. The domain score for this section was 71%.

### ***2.1.3 Rigour of Development***

This domain relates to the process used to gather and synthesize the evidence, the methods to formulate the recommendations, and to update them. One of the reviewers suggested that the literature included as evidence should have included cross-cultural literature in general and should not have been limited to cancer literature. However, the review question was developed in line with the aim and objectives of the research and required a specific focus on cancer literature. Most of the reviewers rated this domain favourably. Three of the reviewers indicated that the strengths and limitations of the body of evidence were not clearly described. Section 4.2 has been added to address this concern. One of the reviewers indicated that the methods for formulating recommendations were not clearly described. This is addressed in section 2.2.3.2. The domain score for this section was 78%.

#### ***2.1.4 Clarity of Presentation***

This domain deals with the language, structure, and format of the guideline. The reviewers scored this domain well. One of the reviewers reported that the most critical recommendations should be highlighted as the recommendations are exhaustive. However, the recommendations are in line with the definition of cultural competence and also add context specific information that will aid in managing the Zulu patient diagnosed with osteosarcoma. Furthermore, the evidence did not prioritise recommendations. The domain score for this section was 87%.

#### ***2.1.5 Editorial Independence***

This domain is concerned with the formulation of recommendations not being unduly biased with competing interests. Two of the reviewers scored this domain favourably. One of the reviewers indicated that funding and conflict of interest related to funding should be specified in the guideline. The suggestion was incorporated into the guideline. The domain score for this section was 80%.

#### ***2.1.6 Overall Guideline Assessment***

The overall quality of the guideline was rated favourably. Two of the guideline reviewers recommended the guideline for use without modification and three reviewers recommended the guideline with modification. General comments made are now briefly outlined:

Reviewer 1:

This reviewer accepted the guideline with modification. Suggestions regarding a modification of the review question and an inclusion of credentials for the guideline developer were made. The relevance of the patient interview questions in addressing the recommendations for inclusion in the guideline, and the number of patients interviewed was queried. More detail regarding the target users was requested and a summary of the strengths and limitations of the body of evidence was proposed. Clearer description of the methods for formulating the recommendations was also suggested. All of these comments have been integrated into the guideline.

Reviewer 2:

This reviewer accepted the guideline with modification. This reviewer reflected on the responsibility that the healthcare provider has in taking cognisance of the vast differences and nuances in treating Zulu speaking patients. The relevance of a guideline of this nature was emphasised.

Reviewer 3:

This reviewer indicated that the guideline was comprehensive and very well described. She made specific suggestions such as referring to the language as isiZulu and specifying the age group used as adult, which have been incorporated into the guideline. Content suggestions were also made with

reference to the recommendations. However these opinions could not be adhered to as the guideline is based on the evidence gathered.

Reviewer 4:

The guideline was well-accepted by this reviewer. This reviewer highlighted the importance of the role of family and community in managing African patients and how this diverges from westernized notions of clinical practice where the patient's right to self-determination is usually in the foreground. The role of family is reflected in the guideline recommendations in sections 3.1.1.4, 3.1.2.4, 3.1.3.4, 3.1.3.5 and 3.2.2.4. This reviewer also inquired about Zulu mysticism and African philosophy regarding limb disposal following amputation. The issue of clinical ethics in MDT functioning was also raised. The patients and healthcare providers interviewed in order to obtain stakeholder accounts did not raise these issues.

Reviewer 5:

The guideline was well-accepted by this reviewer. Content comments and a suggestion that recommendations take the link between patients, family and community into account were made. The link with family is firmly established in the recommendations. Further development of this guideline may explore community aspects.

## **2.2 The Evidence-Based Practice Guideline**

This section provides details on the guideline development process according to the domains of the AGREE II instrument.

### ***2.2.1 Scope and Purpose***

This domain encompasses the aim of the guideline, the review question and the target population.

#### **2.2.1.1 Aim of the guideline**

Research has indicated that patients present at the study site when the disease has already metastasised.<sup>17</sup> Although this is partially due to misdiagnosis at peripheral facilities,<sup>17</sup> focus groups with healthcare providers at the study site and in-depth interviews with Zulu patients treated at the site confirmed observations in clinical practice that cultural health beliefs and practices also contribute to delays in treatment. The aim of this guideline is therefore to present healthcare providers treating adult Zulu patients diagnosed with osteosarcoma with evidence-based recommendations that can facilitate culturally competent communication regarding the diagnosis, treatment and prognosis of osteosarcoma.

### 2.2.1.2 The review question

The review question: How is culturally competent patient-provider communication best delivered by healthcare providers to adult Zulu patients diagnosed with osteosarcoma?

### 2.2.1.3 Target group

The targeted patient population are adult Zulu patients diagnosed with osteosarcoma. The adult age refers to patients 18 years and older.

## **2.2.2 Stakeholder Involvement**

The guideline was developed by one of the members of the multidisciplinary team working with Zulu patients diagnosed with osteosarcoma. The developer is a content expert with methodological experience in both quantitative and qualitative research. The guideline development process was supervised by content and methodological experts.

In addition, the healthcare providers working in a multidisciplinary team context with Zulu patients diagnosed with osteosarcoma participated in focus groups in order to ascertain their current approaches and their suggestions regarding how to engage in culturally competent communication with these patients. Zulu patients' views and preferences were investigated using in-depth interviews.

The evidence-based practice guideline was developed for use amongst healthcare providers working with Zulu patients diagnosed with osteosarcoma. These professionals include doctors, nurses and allied health professionals. The doctors working in the Orthopaedics Department are the first port of call for these patients. Nurses working in orthopaedic and oncology outpatient clinics and wards have the most contact with Zulu patients diagnosed with osteosarcoma. Allied health professionals working with Zulu patients diagnosed with osteosarcoma at the study site include physiotherapists, clinical psychologists, social workers, occupational therapists and dieticians. The guideline has not been piloted with the target group as this task is beyond the scope of the current research study.

## **2.2.3 Rigour of Development**

This domain relates to the process used to gather and synthesize the evidence, the methods to formulate the recommendations, and to update them.

### 2.2.3.1 Gathering and synthesising the evidence

An integrative literature review was conducted to review the existing evidence. In addition, focus groups with healthcare providers and in-depth individual interviews with Zulu patients were conducted in order to contextualise the guideline. The approach taken therefore reflects the general consensus in the literature that evidence-based practice typically includes three key components

namely, research-based evidence available from the literature, clinical expertise and patient preferences.<sup>27,28</sup>

#### 2.2.3.1.1 Integrative Literature Review

An integrative literature review was conducted using Whittemore and Knaff's approach.<sup>29</sup> An experienced librarian assisted the primary author with selecting the keywords and databases, and with conducting the search. In the period February to May 2015, the following electronic databases were searched: PubMed, EBSCOHost, Emerald, JSTOR, Sabinet Online, SAGE, Cochrane, Science Direct, SpringerLink, Taylor and Francis, Web of Science, NEXUS and Sabinet (Thesis/Dissertations). Evidence-based practice guideline websites were also searched, including the National Guideline Clearinghouse, National Health and Medical Research Council (NHMRC), New Zealand Guidelines Group (NZGG), Registered Nurses' Association of Ontario (RNAO), The National Institute for Health and Care Excellence (NICE), Scottish Intercollegiate Guidelines Network (SIGN), eGuidelines, Guidelines International Network, Turning Research into Practice (Trip) Database, Canadian Medical Association (CMA) Infobase and Joanna Briggs Institute (JBI) Evidence-based Practice Database. A manual search was conducted using Google Scholar and the following websites: ([www.culturediversity.org/cultcomp.htm](http://www.culturediversity.org/cultcomp.htm), [www.diversityrx.org/HTML/DIVRX.htm](http://www.diversityrx.org/HTML/DIVRX.htm), [www.omhrc.gov/templates/](http://www.omhrc.gov/templates/), <http://sis.nlm.nih.gov/outreach/multicultural.html>, <http://npin.cdc.gov/pages/cultural-competence>, [www.adventisthealthcare.com/health/equity-and-wellness/www.hrsa.gov/culturalcompetence/qualityhealthservices](http://www.adventisthealthcare.com/health/equity-and-wellness/www.hrsa.gov/culturalcompetence/qualityhealthservices), [www.cancer.gov/aboutnci/organization/crchd](http://www.cancer.gov/aboutnci/organization/crchd), [iccnetwork.org/pocketguide/](http://iccnetwork.org/pocketguide/), [www.cdc.gov/cancer/healthdisparities/statistics/ethnic.htm](http://www.cdc.gov/cancer/healthdisparities/statistics/ethnic.htm)).

The following keywords were used in various combinations to conduct the literature searches: patient-provider communication; doctor-patient communication; physician-patient communication; cancer; oncology; cultural competence; culturally competent communication; cross-cultural communication; multicultural communication; and transcultural communication. Various sets of keywords were used that were deemed suitable for the databases, to ensure that no relevant literature was missed.

The following inclusion criteria were used: relevant literature from 1982 was included, as the term 'cultural competence' first appeared in the literature in 1982.<sup>30</sup> The literature on cultural competence had to pertain specifically to cancer or to cultural aspects of communication in the context of cancer care, and had to be available in English. Owing to the paucity of research documents available on the topic, non-research documents were also included when these were appraised as relevant to the review question.<sup>31</sup> Regarding exclusion of records, literature that pertained to cultural competence in disciplines other than the context of cancer care was excluded from the review. Literature pertaining to paediatric oncology, cancer patient education not related to the interaction between patients and

healthcare providers, and cancer screening, were also excluded. Inclusion and exclusion of records was independently verified by the second author using the inclusion and exclusion criteria.

Data evaluation entailed rating the evidence and critically appraising the records. A comprehensive and frequently used hierarchy system (Table 1) was chosen to rate the evidence.<sup>32</sup> Most of the documents were evaluated as level VII evidence (N=25), eight of the documents fulfil the criteria for level VI evidence, and two of the documents could be evaluated as level IV evidence.

Table 1: Rating System for the Hierarchy of Evidence for Intervention/Treatment Questions<sup>32</sup>

Level I (strongest evidence)	Evidence from a systematic review or meta- analysis of all relevant randomized controlled trials (RCTs) Evidence from evidence-based clinical practice guidelines based on systematic reviews of RCT's
Level II	Evidence obtained from at least one well-designed RCT
Level III	Evidence obtained from well-designed controlled trials without randomization (quasi-experimental study)
Level IV	Evidence from well-designed non-experimental studies (case-control, correlational, cohort studies)
Level V	Evidence from Systematic reviews of descriptive or qualitative studies
Level VI	Evidence from a single descriptive or qualitative study
Level VII	Evidence from the opinion of authorities and/or reports of expert committees

Critical appraisal tools were used to carefully and systematically examine the records in order to judge trustworthiness, value and relevance in a particular context.<sup>33</sup> Documents were critically appraised independently by two reviewers to ensure rigour. Two quantitative studies were appraised using the Health Care Practice Research and Development Unit (HCPREDU) Evaluation Tool for Quantitative Studies.<sup>34</sup> Four qualitative studies were appraised using the Critical Appraisal Skills Programme (CASP) tool for assessing qualitative research.<sup>35</sup> Non-research records (N=29) were appraised using the Johns Hopkins Nursing Evidence-based Practice tool for Non-Research Evidence Appraisal.<sup>31</sup> After critical appraisal was done, thirty-five records were included for data extraction and synthesis.

Data relevant to the review question were extracted from the included records. Data extraction and synthesis were also independently verified to improve the rigour of the data analysis. Data display matrices were developed to facilitate data comparison and synthesis. The researchers employed an

iterative process by repeating the data extraction and synthesis numerous times, in order to ensure the verification of the results.

#### 2.2.3.1.2 Healthcare provider focus groups

Three separate semi-structured focus group interviews were conducted with orthopaedic consultants/registrar, nurses from the orthopaedic and oncology outpatient clinics and wards, and allied health professionals (N=23). The allied health professional focus group consisted of occupational therapists, physiotherapists, dieticians and a social worker. Interview questions focused on approaches that healthcare providers take when discussing osteosarcoma diagnoses, treatment and prognosis with Zulu patients and the cultural considerations pertaining to these discussions. The tertiary hospital where the guideline was developed uses a multidisciplinary approach hence all members of the team working with Zulu patients diagnosed with osteosarcoma were approached for participation in the focus groups (census sampling). Four Zulu healthcare professionals participated in the study. That the majority of the participants were not Zulu is an accurate reflection of the fact that patient-provider encounters are largely culturally discordant at this tertiary hospital. Data was independently coded and analysed using thematic analysis.<sup>36</sup> Data was further reviewed by two independent qualitative research experts before consensus was reached on the themes. Guba's Model of Trustworthiness was used to ensure rigour.<sup>37</sup> The evidence derived from these focus groups can be classified as level VI evidence.

#### 2.2.3.1.3 Patient interviews

Four in-depth interviews were conducted with Zulu patients diagnosed with osteosarcoma. Questions explored how diagnosis, treatment and prognosis were communicated to the patient; what patients understood about their diagnosis and treatment; their experience of the communication; and the role of culture in managing the condition. The questions were designed in order to elicit recommendations for inclusion in the guideline. Convenience sampling was used. There were a number of challenges with regard to locating patients for participation. In addition, distance from the study site also limited the number of patients that could participate. The interviews were conducted in isiZulu, transcribed and then translated for independent coding and thematic analysis by two experienced researchers.<sup>36</sup> Guba's Model of Trustworthiness with its four criteria was utilized to ensure rigour.<sup>37</sup> This study can be classified as level VI evidence.

#### 2.2.3.2 Formulating the recommendations

The recommendations were developed using content analysis. The guideline clearly links the recommendations to the evidence source. References are indicated next to each recommendation. The recommendations were formulated following careful review of the results of the integrative literature review, the focus group interviews and the patient interviews. Duplicate recommendations across

these three sources were grouped together. Generic recommendations were grouped together and recommendations specific for the communication of the diagnosis, treatment and prognosis of osteosarcoma with Zulu patients were presented separately. The guideline was reviewed by an expert panel and should be updated within the next two to three years. A guideline development group did not develop the guideline; however the guideline development process was supervised by experienced researchers and clinicians.

#### ***2.2.4 Clarity of Presentation***

Care was taken to develop clear and unambiguous recommendations. Headings and subheadings clearly demarcate the different sections of the guideline. Appendix A provides a summary of the recommendations, the source of the recommendations and the associated levels of evidence.

#### ***2.2.5 Editorial Independence***

There are no competing interests to report. The research was not funded hence there is no conflict of interest to report with regard to finding.

### **3. Guideline Recommendations**

The recommendations are based on levels IV, VI and VII evidence from the integrative literature review, focus groups with healthcare providers and patient interviews (Appendix A). Cultural competence has varied definitions but seems to require the acquisition, integration and application of awareness, knowledge, skills and attitudes regarding cultural differences in order to effectively deliver expert care that meets the unique cultural needs of patients; to manage and reduce cross-cultural misunderstanding in discordant medical encounters; and to successfully negotiate mutual treatment goals with patients and families from different cultural backgrounds.<sup>15,38-45</sup> The guideline first specifies generic aspects such as the awareness, knowledge, skills, and provider attitudes required for culturally competent communication as well as the type of healthcare systems that can support and cultivate such communication. The guideline then details specific recommendations for communicating the diagnosis, treatment and prognosis of osteosarcoma to Zulu patients. Where references are indicated, the recommendations are based on the integrative literature review.

#### **3.1 Generic requirements for culturally competent communication**

##### *Evidence-based rationale*

Generic requirements for engaging in culturally competent communication include the development of awareness, the acquisition of knowledge, the acquisition and implementation of skills and strategies and fostering certain attitudes.<sup>15,38</sup> The development and practice of culturally competent communication by individual practitioners and multidisciplinary teams is best fostered in the context of culturally competent healthcare systems. Culturally competent healthcare systems provide

linguistically and culturally appropriate services and supportive policies, strategies and resources that promote culturally competent communication.<sup>46</sup> These generic requirements are now stipulated in clearly demarcated subsections.

### **3.1.1 Healthcare provider awareness**

Different types of **healthcare provider awareness** are required for working in cross-cultural oncology settings. The acquisition, integration and application of awareness of cultural differences in cross-cultural oncology settings encompass more than just an awareness of self. The evidence revealed that HCPs have to develop contextual, self, and interpersonal awareness as well as an awareness of cultural expectations in the healthcare setting.

3.1.1.1 It is recommended that healthcare providers **develop contextual awareness** of:

- the country's socio-political history<sup>47</sup>
- the sociocultural factors that affect the patient-provider relationship<sup>48</sup>
- patient demographics in the service area<sup>49,50</sup>
- the role of gender in culture<sup>50,51</sup>
- the role of religion in culture<sup>50,51</sup>
- patients' level of education<sup>52,53</sup>
- patients' experiences of discrimination in clinical settings<sup>54</sup>
- dominant cultural narratives regarding health and illness<sup>55</sup>
- culturally constructed myths about cancer<sup>56</sup>
- cancer patients possibly combining allopathic and traditional medicine<sup>55</sup>

3.1.1.2 It is recommended that healthcare providers **develop self-awareness** of own:

- culture<sup>57</sup>
- cultural beliefs<sup>58</sup>
- belief systems<sup>59</sup>
- spirituality<sup>60</sup>
- cultural assumptions, biases and stereotypes<sup>14,48,57,59,61</sup>

3.1.1.3 It is recommended that healthcare providers **develop interpersonal awareness** of:

- inherent power differentials between patient and provider<sup>47</sup>
- interaction between patient and provider's culture<sup>57,62</sup>
- communication differences between cultures<sup>51,63</sup>

3.1.1.4 It is recommended that healthcare providers **develop awareness of cultural expectations in the healthcare setting** related to the:

- level of family involvement required<sup>59,64</sup>
- role of family in cross-cultural clinical settings<sup>15,50,64,65</sup>

### **3.1.2 Healthcare provider knowledge**

Culturally competent communication requires the acquisition, integration and application of knowledge regarding the context, the self, and the patient's culture.

3.1.2.1 It is recommended that healthcare providers **acquire knowledge of broader contextual factors** pertaining to:

- racism, sexism, ageism<sup>58,66</sup>
- socio-political barriers to accessing healthcare<sup>14,61,67</sup>
- the impact of past and present racism<sup>61</sup>
- the role of gender in the communication process<sup>14</sup>
- the role of age in the communication process<sup>14</sup>
- patients' role expectations in the communications process<sup>14</sup>
- socio-historical cultural context<sup>14</sup>
- socio-cultural differences between self and patient<sup>61</sup>

3.1.2.2 It is recommended that healthcare providers **acquire context specific knowledge** of:

- the cultural groups attending services in the provider's clinical setting<sup>49,61,63,65,67,68</sup>
- serviced population's disease profiles, health disparities and treatment outcomes<sup>44,63</sup>
- cultural health-related needs and health-seeking behaviours<sup>61</sup>
- cultural approaches to illness and treatment<sup>48</sup>
- cultural meanings of cancer<sup>14</sup>
- patients' perception of their illness<sup>63</sup>
- influence of culture on how patient interacts with healthcare system<sup>59</sup>

3.1.2.3 It is recommended that healthcare providers **acquire self-knowledge** of own:

- culture<sup>55,61,63,67</sup>
- belief system<sup>61</sup>
- biases and stereotypes<sup>14,59,61,67</sup>

3.1.2.4 It is recommended that healthcare providers **acquire knowledge of the patient's culture**, specifically:

- the patient's health belief systems<sup>54,64,67</sup>
- the patient's traditional health system<sup>64</sup>
- the role of gender in decision-making<sup>49,64</sup>
- the role of family in decision-making<sup>49,64</sup>
- preferences regarding language used to discuss cancer<sup>15</sup>
- nonverbal communication standards<sup>15</sup>

### **3.1.3 Healthcare provider skills**

The healthcare provider is expected to acquire, integrate and apply a variety of skills in order to successfully deliver culturally competent patient-provider communication.

3.1.3.1 It is recommended that healthcare providers deliver culturally and linguistically sensitive services by **acquiring and applying** the following **cross-cultural communication skills**:

- Engage in culturally sensitive communication recognising the values beliefs and practices of the patient and presenting the communication accordingly<sup>14,15,56,69</sup>
- Engage in culturally congruent communication which recognises that cultural variations exist between patient and HCP and engages in culturally sensitive and competent communication accordingly<sup>14,67</sup>
- Observe culturally appropriate nonverbal communication etiquette<sup>14</sup>
- Use congruent verbal and nonverbal communication<sup>14,67</sup>

3.1.3.1.1 It is recommended that healthcare providers **ensure patient understanding** by acquiring and applying the following communication skills and strategies:

- Provide clear,<sup>64,67</sup> accurate,<sup>64,67</sup> open,<sup>53,54,60,70</sup> flexible<sup>53</sup> and transparent<sup>60</sup> communication
- Provide information in the patient's language<sup>64</sup>
- Learn the language<sup>64</sup>
- Develop a vocabulary of terms familiar to the patient<sup>64</sup>
  - Include some basic isiZulu phrases in conversations [focus groups]
- Use language that patients can understand [focus groups]
- Use simple language<sup>47,52-54</sup> [focus groups]
- Encourage the patient to ask questions<sup>51</sup> [focus groups]
- Repeat information several times<sup>47</sup> [focus groups]
- Check patient understanding of information<sup>47,54,62-64,69</sup> [focus groups]
- Check what patients remember from previous explanations [focus groups]

- Do not use medical jargon [focus groups]

3.1.3.2 It is recommended that healthcare providers **manage differences in the patient-provider encounter:**

- Avoid stereotyping and generalisations<sup>14,44,48,61,63,64,67</sup> [focus groups]
- Do not make assumptions about patient race, nationality and language<sup>15</sup> [focus groups and patient interviews]
- Treat patients equally<sup>52,53</sup>
- Encourage patients to raise concerns about discrimination<sup>54</sup>
- Create a culturally safe and caring environment<sup>47,70</sup>
- Individualise patient care<sup>48,70</sup>

3.1.3.3 It is recommended that healthcare providers **build the patient-provider relationship:**

- Invest time in the beginning<sup>49,63,71</sup>
- Engage the patient<sup>67</sup>
- Build rapport<sup>47,51</sup>
- Gain patient trust<sup>38,51,53,56,67</sup>
- Respond to patients' emotions [focus groups & patient interviews]
- Actively engage patients in decision-making<sup>51,63,69</sup> [focus groups]
- Encourage and empower patients to raise trust issues<sup>54</sup>
- Address patients according to cultural preference<sup>67</sup>
- Recognise inherent power differentials<sup>67</sup>
- Be open about own cultural frame of reference<sup>55</sup>
- Acknowledge own cultural background to patients<sup>15</sup>
- Respond skilfully to cultural discordance<sup>67</sup>

3.1.3.4 It is recommended that healthcare providers **conduct a comprehensive patient assessment:**

- Assess patients' specific communication needs<sup>71</sup>
- Conduct a cultural assessment by actively exploring patients' culture:<sup>60,62,71</sup>
  - Invite patients to describe their cultural backgrounds<sup>68</sup>
  - Explore views on family and community in the healthcare context<sup>68</sup>
  - Explore cultural<sup>67</sup> and health beliefs<sup>59</sup>
  - Explore family expectations, feelings and concerns<sup>60</sup>
  - Explore level of family involvement required<sup>59</sup>
  - Determine who the main decision-makers are (patient or family?)<sup>48,49</sup> [patient interviews]
  - Explore preferences for truth disclosure<sup>15,59,63</sup>

- Explore patients' spiritual and religious beliefs<sup>15,60</sup>
- Ask patients about their disease process [focus groups]
  - Use Kleinman's eight questions<sup>38,68</sup>

3.1.3.5 It is recommended that healthcare providers **acquire and apply the skill of accommodating the patients' family:**

- Invest in and gain family trust<sup>52,67</sup>
- Communicate with extended family as per patient's directive<sup>67</sup> [focus groups]
- Afford the family maximum control possible if this is a patient need<sup>60</sup>

3.1.3.6 It is recommended that healthcare providers **instil and maintain hope regardless of the disease stage** by [focus groups]:

- Emphasising what **can** be done
  - Inform patients that a palliative amputation could help with pain management
- Reassuring patients of continued involvement of the multidisciplinary team
- Differentiating the different problems that would be addressed
- Explaining how the different problems would be addressed
- Avoiding the provision of false hope
  - Do not inform patients that amputation could cure due to the possibility of disease recurrence

### ***3.1.4 Healthcare provider attitudes***

It is recommended that healthcare providers **cultivate and integrate** the following **attitudes** in order to facilitate culturally competent communication:

- Take responsibility for cultural aspects of health and illness<sup>48</sup>
- Take responsibility for combating discrimination in healthcare settings<sup>48</sup>
- Take responsibility for learning about the Zulu culture [focus groups]
- Be willing to learn from patients<sup>67</sup>
- Be open to change and growth<sup>70</sup>
- Be culturally sensitive<sup>15,48,70</sup>
- Be willing to listen<sup>70</sup>
- Develop and demonstrate respect for cultural diversity, for the patient's culture and their cultural values<sup>15,48,53,54,59,65,66,67</sup>
- Demonstrate respect for patients' spiritual and religious beliefs<sup>52</sup>
- Develop an appreciation of different health belief systems<sup>66</sup>
- Be willing to explore culture with individual patients<sup>63</sup>

- Validate different cultures<sup>68</sup>
- Engage in continual self-examination and self-reflection to examine one's own values and assumptions<sup>58,61,70</sup>
- Be willing to adjust behaviours and attitudes<sup>63</sup>
- Reflect on own interaction with cultural groups in the clinical setting<sup>63</sup>

### **3.1.5 Culturally competent healthcare systems**

**Culturally competent healthcare systems** are a requirement for the delivery of culturally competent communication.

3.1.5.1 It is recommended that healthcare systems cultivate the following **characteristics**:

- Are responsive to individual needs and to how cultures are perceived<sup>56,61</sup>
- Promote and facilitate effective patient-centred communication<sup>61</sup>
- Respect cultural differences, and support effective care for diverse populations<sup>61</sup>
- Provide ethnic-specific services<sup>14</sup>
- Convert an awareness of disease prevalence into practices and policies<sup>44</sup>
- Develop and implement policies to support effective cross-cultural communication<sup>61,70</sup>
- Link with culturally competent agencies and community organisations that provide bilingual and bicultural navigation, promotions, and community health outreach services<sup>14</sup>
- Have adequate support services<sup>70</sup>
- Include traditional healers in patient care [focus groups]

3.1.5.2 It is recommended that healthcare systems employ the following cultural competence **strategies**:

- Use patient navigators<sup>42,49,51,67,72,73</sup>
- Use experienced and professional interpreters<sup>14,15,38,48,51,54,56,59,64,68</sup>
- Use culturally sensitive print, visual, and audio-visual media and electronic communication<sup>51,54,69</sup>
- Use images to assist providers when discussing cancer with patients<sup>47</sup> [focus groups]
- Monitor patient characteristics<sup>54</sup>
- Translate written communications<sup>48</sup>
- Provide language-concordant encounters<sup>54</sup>
- Provide patient-centred care<sup>72</sup>
- Consult communities on cultural needs<sup>47</sup>
- Integrate community resources into cancer care<sup>14</sup>
- Display images of people from cultural groups attending the service<sup>47</sup>
- Have ethnically similar staff visible<sup>47</sup>

### **3.2 Recommended strategies for communicating the diagnosis, treatment and prognosis of osteosarcoma**

The focus groups and patient interviews revealed specific strategies for communicating the diagnosis of osteosarcoma to Zulu patients. General recommendations for discussing treatment as well as proposed strategies for managing cultural factors that affect treatment are outlined. Prognosis discussion recommendations are less extensive but still provide some guidance on how to approach this challenging task.

#### **3.2.1 Recommended strategies for communicating the diagnosis of osteosarcoma to Zulu patients**

##### *Evidence-based rationale*

Communicating the diagnosis of cancer in cross-cultural clinical settings is documented as a challenging task.<sup>74</sup> Results from the focus group interviews with healthcare providers highlighted distinctive factors that complicate communicating the diagnosis of osteosarcoma to Zulu patients. The Zulu people generally view the cancer diagnosis as an ancestral punishment or resulting from witchcraft and have been socialised to associate a cancer diagnosis with a poor prognosis. The isiZulu word for cancer reflects these cultural health beliefs and presents a significant barrier as the meanings associated with this word significantly complicates the diagnosis discussion especially when a good prognosis is possible. The isiZulu word for cancer is *umdlavuzza* and refers to something that ravages, destroys, or cannot be stopped. Furthermore, language barriers present a significant challenge in this cross-cultural setting. The lack of availability of medical terms in isiZulu and the limitations with regard to the translatability of words into the patient's language significantly impacts patient understanding. Language barriers further manifest in the lack of access to professional interpreters. Communicating the diagnosis of osteosarcoma to the Zulu patients therefore requires an understanding of cultural and health beliefs and incorporating this knowledge into diagnostic conversations.

3.2.1.1 It is recommended that healthcare providers provide patients **with factual information** about their condition including [patient interviews]:

- Its name
- Prevalence
- Causes

3.2.1.2 It is recommended that healthcare providers **set the stage for truth-telling** by:

- Starting the diagnosis discussion right from the beginning [focus groups]
- Assessing how much the patient knows

- Warning patients a few times about possible cancer diagnosis [focus groups and patient interviews]
- Giving patient incremental information as the diagnostic process unfolds [focus groups]
- Informing patients of the reasons for diagnostic tests [focus groups and patient interviews]
- Warning patients before delivering bad news when the diagnosis is confirmed [focus groups and patient interviews]
- Warning patients by reminding them of earlier conversations of possible diagnosis [focus groups]
- Checking patients' readiness to receive the diagnosis [patient interviews]
- Offering privacy when communicating the diagnosis [patient interviews]
- Confirming diagnosis only once patient has been warned [focus groups and patient interviews]

3.2.1.3 It is recommended that healthcare providers **engage in patient-centred communication** by:

- Building a relationship with the Zulu patient (see 3.1.3.3) [focus groups]
- Spending time with the patient [focus groups]
- Offering the patient support [focus groups]
- Demonstrating a personal interest in the patient [focus groups]
- Assessing and addressing patient needs, emotions and coping [focus groups and patient interviews]
- Responding to patient questions about the diagnosis [focus groups]
- Assessing patients' reactions to the diagnosis [focus groups]
- Responding appropriately to patients' reactions to the diagnosis [focus groups]
- Managing the response of denial by [focus groups]
  - acknowledging that the diagnosis is difficult to accept
  - reinforcing the diagnosis
  - helping patients to accept the diagnosis
- Mobilising support by having a psychologist present when patients are informed of the diagnosis [focus groups]

3.2.1.4 It is recommended that healthcare providers **engage in culture-centred communication** by:

- Taking responsibility for improving communication (see also 3.1.3.1.1) [focus groups]
- Demonstrating an understanding of Zulu cultural health beliefs [focus groups]
- Reassuring patients that their diagnosis is [focus groups]:
  - not due to anything that they have done
  - not a punishment
  - not due to bewitchment
- Demonstrating a genuine interest in the Zulu culture by [focus groups]:

- Asking patients questions about (see also 3.1.3.4)
  - their cultural practices
  - their religious practices
  - their understanding of the aetiology of the condition
  - how they want to manage the condition
  - their cultural health beliefs
- Offering patients the best care possible regardless of language discordance [focus groups]

3.2.1.5 It is recommended that healthcare providers **facilitate understanding of the diagnosis** by [focus groups]:

- Using visual aids
  - Use images, pictures and information brochures
- Explaining the stages of cancer
  - Educate patients regarding their stage of the disease
  - Educate patients about the effects of cancer in every stage
- Using metaphors
  - Use metaphors to explain concepts like cells, organs, tumours and metastases
  - Use patient-initiated metaphors

### ***3.2.2 Recommended strategies for communicating the treatment of osteosarcoma to Zulu patients***

#### *Evidence-based rationale*

Owing to the late presentation of patients for treatment at the study site (Ferreira), treatment options are limited and prognoses are often poor. Healthcare professionals (HCPs) consequently have to simultaneously inform patients of the diagnosis of osteosarcoma as well as the significant limitations with regard to treatment options. Late presentation means that most patients are not eligible for limb salvage and have to be informed about amputation.<sup>17</sup> A number of cultural factors have been identified with regard to discussing the treatment option of amputation with Zulu patients. Healthcare providers reported in the focus group interviews that Zulu patients' cultural beliefs dictate that they cannot become an ancestor if they have an amputation because their body is incomplete. The issue of post-amputation community exclusion was also raised. The patient interviews also revealed that cultural considerations become important when treatment, specifically amputation, is discussed. Focus groups and patient interviews also indicated other Zulu cultural and health beliefs that affect treatment such as the belief in traditional healing and the need to consult with cultural decision-makers before agreeing to treatment. The recommendations on how to communicate with Zulu patients regarding the treatment of osteosarcoma therefore take these cultural beliefs and practices into account.

3.2.2.1 It is recommended that healthcare providers **provide patients with factual information** pertaining to [focus groups and patient interviews]:

- Surgical treatment options
  - Limb salvage is explained if this is an option
  - Amputation is discussed if it is the only option or in the case of borderline tumours
- Chemotherapy
  - Its purpose
  - When and how it will be used
  - Side-effects of chemotherapy (emphasised in patient interviews)
- Treatment of metastases (metastasectomies and/or chemotherapy)

3.2.2.2 It is recommended that healthcare providers follow this **process when discussing treatment** with patients:

- Delay providing treatment information until staging investigations are completed
- Inform patients about the prognostic consequences of not treating the tumour, e.g. metastases, shortened life-span [focus groups and patient interviews]
- Balance hope and honesty [focus groups] by
  - Communicating the urgency of intervening [patient interviews]
  - Offering patients reassurance [patient interviews]
- Ensure patient understanding by (see also 3.1.3.1.1) [focus groups]:
  - Using analogies
  - Using the stages of cancer to explain disease progression and realistic treatment options.
- Explore and manage patients' emotions associated with amputation and chemotherapy [patient interviews]

3.2.2.3 It is recommended that healthcare providers use these **strategies for responding to cultural factors associated with amputation** [focus groups]:

- Time the treatment discussion to prevent the patient from signing refusal of hospital treatment (RHT) before diagnostic testing is complete.
- When patients refuse amputation, offer patients other treatment options like chemotherapy and refer patients to other services like oncology, psychology, social work and dietetics.
- Mobilise support by having a psychologist present when patients are informed of that an amputation is required
- Expose patients to veteran osteosarcoma patients who have successfully adjusted to amputation
- Show newly diagnosed patients a video of patients with successful outcomes

3.2.2.4 It is recommended that healthcare providers use these **strategies for responding to cultural and health beliefs that affect treatment**:

- Initiate cultural discussions in order to fast track decision-making [focus groups]
- Demonstrate an understanding of patients' cultural beliefs by:
  - Acknowledging patients' need to discuss treatment with their family [focus groups]
  - Encouraging patients to engage in their cultural traditions and rituals [focus groups and patient interviews]
  - Encouraging patients to combine Western and traditional approaches [focus groups and patient interviews]
  - Respecting patients' cultural health beliefs and their desire to consult traditional healer [focus groups and patient interviews]
- Liaise directly with family and cultural decision-makers where possible [focus groups]
- Negotiate with patients to not go home and to rather invite a family member(s) to the hospital [focus groups]

### ***3.2.3 Recommended strategies for communicating prognostic information pertaining to osteosarcoma with Zulu patients***

Evidence-based rationale

Given the late presentation of patients at the study site, HCPs have to communicate diagnostic and treatment information urgently. The treatment options are closely related to patients' understanding of their prognosis and the outcomes resulting from various approaches to treatment.

3.2.3.1 It is recommended that healthcare providers **assess patient emotions and knowledge** by:

- Enquiring about patients' thoughts, fears, and impressions of the future [focus groups]

3.2.3.2 It is recommended that healthcare providers **inform patients of the prognostic consequences of not treating the osteosarcoma** [focus groups and patient interviews]:

- Inform patients of the likelihood of metastases if the osteosarcoma was not treated.
- Inform patients of the effect on survival if the osteosarcoma was not treated.

3.2.3.3 It is recommended that healthcare providers **inform patients of treatment limitations**:

- Explain the nature of osteosarcoma to patients and inform patients that this type of cancer is not curable [focus groups]
- Inform patients that even with surgery the cancer could recur [focus groups and patient interviews]

- Inform patients that they have to return within six months and then annually to check for cancer recurrence [focus groups and patient interviews]

3.2.3.4 When patients have **metastases**, it is recommended that healthcare providers inform patients that:

- That they have metastases [focus groups and patient interviews]
- The condition is not curable but that amputation could help with pain [focus groups]
- Treatment options are limited due to the metastases [focus groups]

3.2.3.5 It is recommended that healthcare providers **inform patients of poor prognoses**:

- Inform patients about the terminal nature of the disease if the osteosarcoma is reasonably expected to result in the death of the patient within a short period of time [focus groups]
- Normalise death [focus groups]
- Do not inform patients of the life expectancy [focus groups]

3.2.3.6 It is recommended that healthcare providers **use a staged approach** to communicating about prognosis [focus groups]. Given the late presentation of patients at this tertiary hospital, a staged approach may be more useful for patients that present with localised or metastatic disease that is amenable to surgical management.

- Communicate about immediate treatment goals and if the disease progresses, communicate about adjustments in treatment goals to for example palliative care.
- If treatment is working and cancer is remitting, communicate with patients about rehabilitation and resuming normal everyday activities.

## **4. Strengths and Limitations of the Body of Evidence**

### **4.1 Strengths**

The strengths of the body of evidence are reflected in the actions taken to ensure scientific rigour while collecting the data. With regard to the integrative literature review, an established approach was used to conduct the review.<sup>29</sup> In addition, an independent reviewer experienced in the integrative literature review methodology verified the inclusion and exclusion of records, independently appraised the documents, and verified the data extraction and content analysis of the data extracted from the included documents. Guba's Model of Trustworthiness was used as a guide to ensure the scientific rigour of the studies conducted with the healthcare providers and the Zulu patients.<sup>37</sup> The focus group interviews were conducted by an experienced qualitative researcher in order to minimise bias as the primary investigator is part of the MDT that treats Zulu patients diagnosed with osteosarcoma. The focus group interviewer and the primary investigator independently coded the data

which was further reviewed by two qualitative research experts. The data analysis process was extensive and iterative. The interviews with Zulu patients were conducted by Zulu fieldworkers and the consent form was also available in isiZulu. Patients were encouraged to express themselves freely and also advised that they could withdraw from the study at any time without any recourse. The data from these interviews were translated into English and back translated to ensure accuracy of translation. Data was independently coded by a qualitative research expert and themes were then agreed upon. The research designs and methodologies for all the studies were described in detail and allows for replicability of the work.

#### **4.2 Limitations of the Study**

The evidence derived from the integrative literature review was mostly low level evidence (Level VII) and hence the results had to be interpreted with caution.<sup>32</sup> Furthermore, most of the studies that met the inclusion criteria for inclusion in the integrative literature review were international. With regard to the focus groups with healthcare providers, all those that were eligible to participate were approached but some MDT members were not available at the time of data collection. Our use of discipline specific focus groups likely enhanced our ability to explore issues common to each professional group, however it may have restricted our opportunity to assess the inter-professional functioning of MDT members, which is likely an important factor given the high pressure environment in which the study was conducted. Our results may have been enhanced had other qualitative data gathering techniques been used to complement the focus group interviews. With regard to the patient interviews, patients were asked to provide retrospective accounts of their experiences and the interviews were conducted at one point in time and not as the disease process unfolded. Furthermore, the challenges experienced with regard to locating participants limited the size of the sample. Although a Zulu interviewer ensured that patients could express themselves in their own language, the interviewer already knew what patients meant with regard to some of the cultural aspects that were discussed and hence these were not further explored. Zulu patients' accounts of how prognosis was communicated were limited in comparison to the healthcare providers' descriptions of the prognosis communication.

#### **5. Implementation and Further Development of the Guideline**

Healthcare providers will require cultural competence and communication training in order to facilitate the implementation of the guideline. Focus group interviews highlighted competency issues and lack of training with regard to communicating diagnosis, treatment and prognosis with patients. Furthermore, some of the challenges identified in the focus group interviews are not addressed in this guideline as specific recommendations pertaining to these challenges did not emerge from the data. These challenges included: competency and training deficits with regard to culturally competent

communication of diagnosis and prognosis; lack of clear documentation as to previous patient communication; delays in patient queries being addressed; attendance and continuity of MDT meetings which was particularly difficult due to resource constraints; lack of access to professional interpreters; and nursing time constraints; lack of agreement regarding informing and timing of prognostic information; and lack of knowledge of disease progression in allied health professional staff. Although most of these challenges are organisational in nature, further development of this guideline could include recommendations for addressing these challenges. One of the reviewers enquired about patient satisfaction surveys or audits. This may be a method for obtaining patient feedback at the time of their visit to the hospital thereby circumventing retrospective accounts and difficulties with access to patients at a later stage. This method could also increase the number of patients interviewed. One of the reviewers also proposed that recommendations may be aligned to specific healthcare providers for ease of implementation.

## **6. Conclusion**

Communicating with patients about cancer in cross-cultural clinical settings is widely recognized as a challenging task. The focus on Zulu patients diagnosed with osteosarcoma stems from the fact that these patients present late for treatment and are then faced with making significant treatment decisions which are often viewed as culturally discordant. Zulu cultural and health beliefs affect the speed at which health professionals can intervene and necessitates the appropriate communication with Zulu patients in order to achieve the best cultural and medical outcome.

This evidence-based practice guideline was developed based on evidence derived from an integrative literature review, focus groups with healthcare providers that work with Zulu patients diagnosed with osteosarcoma, and interviews with patients diagnosed with osteosarcoma. The AGREE II tool was used to guide the development of the guideline. Further development of the guideline is needed in order to address some of the challenges identified in the focus group interviews with healthcare providers.

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**Appendix A**  
**Guideline Recommendations and Levels of Evidence**

**Source of Recommendation Key:**  
 Integrative literature review – ILR  
 Focus groups with healthcare professionals – FG  
 In-depth interviews with patients - PI

Generic requirements for culturally competent communication			
Guideline Recommendations		Source of Recommendation	Levels of Evidence
Healthcare provider awareness	Develop contextual awareness	ILR	Level IV, VI, VII
	Develop self-awareness	ILR	Level VI, VII
	Develop interpersonal awareness	ILR	Level VI, VII
	Develop awareness of cultural expectations in the healthcare setting	ILR	Level VI, VII
Healthcare provider knowledge	Acquire knowledge of broader contextual factors	ILR	Level VI, VII
	Acquire context specific knowledge	ILR	Level VI, VII
	Acquire self-knowledge	ILR	Level VII
	Acquire knowledge of the patient's culture	ILR	Level VII
Healthcare provider skills	Acquire and apply cross-cultural communication skills	ILR	Level VII
	Ensure patient understanding	ILR, FG	Level IV, VI, VII
	Manage differences in the patient-provider encounter	ILR, FG, PI	Level IV, VI, VII
	Build the patient-provider relationship	ILR, FG, PI	Level IV, VI, VII
	Conduct a comprehensive patient assessment	ILR, FG	Level VI, VII

	Accommodate the patients' family	ILR, FG	Level VI, VII
	Instil and maintain hope regardless of the disease stage	FG	Level VI
Healthcare provider attitudes	Take responsibility for cultural aspects of health and illness	ILR	Level VI
	Take responsibility for combating discrimination in healthcare settings	ILR	Level VI
	Take responsibility for learning about the Zulu culture	FG	Level VI
	Be willing to learn from patients	ILR	Level VII
	Be open to change and growth	ILR	Level VI
	Be culturally sensitive	ILR	Level VI, VII
	Be willing to listen	ILR	Level VI
	Develop and demonstrate respect for cultural diversity, for the patient's culture and their cultural values	ILR	Level IV, VI, VII
	Demonstrate respect for patients' spiritual and religious beliefs	ILR	Level VII
	Develop an appreciation of different health belief systems	ILR	Level VII
	Be willing to explore culture with individual patients	ILR	Level VII
	Validate different cultures	ILR	Level VII
	Engage in continual self-examination and self-reflection to examine one's own values and assumptions	ILR	Level VI, VII
	Be willing to adjust behaviours and attitudes	ILR	Level VII
Reflect on own interaction with cultural groups in the clinical setting	ILR	Level VII	
Culturally competent healthcare systems	Cultivate the characteristics of culturally competent healthcare systems	ILR, FG	Level VI, VII
	Strategies employed by culturally competent healthcare systems	ILR, FG	Level IV, VI, VII
<b>Recommended strategies for communicating the diagnosis, treatment and prognosis of osteosarcoma</b>			
Guideline Recommendations		Source of	Levels of Evidence

		Recommendation	
Recommended strategies for communicating the diagnosis of osteosarcoma to Zulu patients	Provide patients with factual information	PI	Level VI
	Set the stage for truth-telling	FG, PI	Level VI
	Engage in patient-centred communication	ILR, FG, PI	Level IV, VI, VII
	Engage in culture-centred communication	ILR, FG	Level IV, VI, VII
	Facilitate understanding of the diagnosis	FG	Level VI
Recommended strategies for communicating the treatment of osteosarcoma to Zulu patients	Provide patients with factual information	FG, PI	Level VI
	Follow a specific process when discussing treatment	ILR, FG, PI	Level IV, VI, VII
	Strategies for responding to cultural factors associated with amputation	FG	Level VI
	Strategies for responding to cultural and health beliefs that affect treatment	FG, PI	Level VI
Recommended strategies for communicating prognostic information pertaining to osteosarcoma with Zulu patients	Assess patient emotions and knowledge	FG	Level VI
	Inform patients of the prognostic consequences of not treating the osteosarcoma	FG, PI	Level VI
	Inform patients of treatment limitations	FG, PI	Level VI
	Inform patients regarding metastases and treatment limitations result from the metastases	FG, PI	Level VI
	Inform patients of poor prognoses	FG	Level VI
	Use a staged approach when patients have non-metastatic or minimally metastasised disease	FG	Level VI

## **Appendix I: AGREE II Items**

**AGREE II Items for the Five Domains that were used to Score the  
Evidence-Based Practice Guideline**

Each item is scored according to a 7-point scale with response options ranging from strongly disagree to strongly agree.

<b>DOMAIN 1: SCOPE AND PURPOSE</b>
1. The overall objective(s) of the guideline is (are) specifically described 2. The health question (s) covered by the guideline is (are) specifically described 3. The population (patients, public etc.) to whom the guideline is meant to apply is specifically described
<b>DOMAIN 2: STAKEHOLDER INVOLVEMENT</b>
4. The guideline development group includes individuals from all relevant professional groups 5. The views and preferences of the target population (patients, public, etc.) have been sought 6. The target users of the guideline are clearly defined
<b>DOMAIN 3: RIGOUR OF DEVELOPMENT</b>
7. Systematic methods were used to search for evidence 8. The criteria for selecting the evidence are clearly described 9. The strengths and limitations of the body of evidence are clearly described 10. The methods of formulating the recommendations are clearly described 11. There is an explicit link between the recommendations and the supporting evidence 12. The guideline has been externally reviewed by experts prior to its publication
<b>DOMAIN 4: CLARITY OF PRESENTATION</b>
13. The recommendations are specific and unambiguous. 14. Key recommendations are easily identifiable
<b>DOMAIN 5: EDITORIAL INDEPENDENCE</b>
15. The views of the funding bodies have not influence the content of the guideline

<b>OVERALL GUIDELINE ASSESSMENT</b>
1. Rate the overall quality of the guideline
2. I would recommend this guideline for use: Yes Yes, with modification No

<b>NOTES</b>
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