

Culturally competent patient–provider communication with Zulu patients diagnosed with osteosarcoma: an evidence-based practice guideline

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Abstract

Background

This guideline was developed as a response to patients with osteosarcoma presenting late for treatment thereby significantly affecting their prognoses. Healthcare providers recognised the role of culture and the importance of culturally competent communication in addressing this problem.

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

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 four content and methodological experts using the AGREE II tool.

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. Specific recommendations for communicating the diagnosis, treatment and prognosis of osteosarcoma to Zulu patients were also included.

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. Evidence-based practice can contribute to improving culturally competent communication with cancer patients receiving treatment at culturally discordant healthcare facilities.

Level of evidence: Level 5

Keywords: evidence-based practice guideline, cancer, osteosarcoma, cultural competence, patient–provider communication, cross-cultural clinical settings

Introduction

Communicating the diagnosis and prognosis of cancer is known to be challenging.¹⁻¹⁰ Furthermore, ensuring that patients understand their treatment options is considered good practice.¹¹ Performing these communication tasks in cross-cultural clinical settings complicates patient-provider communication.¹² 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.^{13,14} Culture also affects providers' and institutions' approach to minority patients and contributes substantially to disparities in access to healthcare for minority and underprivileged patients.^{14,15} An evidence-based practice guideline (hereafter referred to as 'guideline') would contribute significantly to improving culturally competent communication with cancer patients receiving treatment at culturally discordant healthcare facilities. A guideline of this nature does not exist in the South African context.

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 11.5 million (of a total South African population of 59.6 million), the majority of which is classified as Zulu.¹⁶ 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 options in the management of osteosarcoma.

In addition, research findings indicated that most patients presenting at the study site already have locally advanced or metastatic disease.¹⁷ 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.¹⁸⁻²¹

Despite advances in treatment of osteosarcoma, survival is dependent on diagnosis prior to progression beyond localised disease.²² The late presentation of patients therefore limits treatment options and results in poor prognosis.^{17,23-26} 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.

Methods

The AGREE II (Appraisal of Guidelines, Research and Evaluation) appraisal instrument was used as a guide for developing the guideline.²⁷ The AGREE II is a 23-item tool comprising six domains.

Scope and purpose

The aim of the developed 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.

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 three focus groups, and four Zulu patients' views and preferences were investigated using in-depth interviews.

The evidence-based practice guideline was developed for use among 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.

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.²⁸ In addition, focus groups with healthcare providers¹⁸⁻²¹ and in-depth individual interviews with Zulu patients²² 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.^{29,30} The recommendations included in the guideline were developed using content analysis. The guideline development process was supervised by content and methodological experts. In addition, the guideline was also reviewed by expert reviewers comprising four content and methodological experts. Their reviews showed consensus.

Guideline recommendations

The recommendations are based on levels 4 and 5 evidence from the integrative literature review, focus groups with healthcare providers and patient interviews. A comprehensive and frequently used hierarchy system was used to rate the evidence.³¹

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.^{15,33-41} 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.

Results

The guideline includes findings that encompass generic recommendations for culturally competent communication and specific recommendations communicating about osteosarcoma.

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.^{15,33,34} The development and practice of culturally competent communication by individual practitioners and multi-disciplinary 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.⁴²

Generic recommendation 1: Healthcare provider awareness

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

It is recommended that healthcare providers develop contextual awareness of:

- the country's socio-political history⁴¹
- the socio-cultural factors that affect the patient-provider relationship⁴²
- patient demographics in the service area^{43,44}
- the role of gender in culture^{44,45}
- the role of religion in culture^{45,46}
- patients' level of education^{46,47}
- patients' experiences of discrimination in clinical settings⁴⁸
- dominant cultural narratives regarding health and illness⁴⁹
- culturally constructed myths about cancer⁵⁰
- cancer patients possibly combining allopathic and traditional medicine⁴⁹

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

- culture⁵¹
- cultural beliefs⁵²
- belief systems⁵³
- spirituality⁵⁴
- cultural assumptions, biases, and stereotypes^{14,42,51,53,55}

It is recommended that healthcare providers develop interpersonal awareness of:

- inherent power differentials between patient and provider⁴¹
- interaction between patient and provider's culture^{51,56}
- communication differences between cultures^{45,57}

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

- level of family involvement required^{53,58}
- role of family in cross-cultural clinical settings^{15,44,58,59}

Generic recommendation 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.

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

- racism, sexism, ageism^{52,60}
- socio-political barriers to accessing healthcare^{14,55,61}
- the impact of past and present racism⁵⁵
- the role of gender in the communication process¹⁴
- the role of age in the communication process¹⁴
- patients' role expectations in the communications process¹⁴
- socio-historical cultural context¹⁴
- socio-cultural differences between self and patient⁵⁵

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

- the cultural groups attending services in the provider's clinical setting^{43,55,57,59,61,62}
- the serviced population's disease profiles, health disparities and treatment outcomes^{38,57}
- cultural health-related needs and health-seeking behaviours⁵⁵
- cultural approaches to illness and treatment⁴²
- cultural meanings of cancer¹⁴
- patients' perception of their illness⁵⁷
- influence of culture on how patient interacts with healthcare system⁵³

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

- culture^{49,55,57,61}
- belief system⁵⁵
- biases and stereotypes^{14,53,55,61}

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

- the patient's health belief systems^{18,48,58,61}
- the patient's traditional health system^{18,58}
- the role of gender in decision-making^{43,58}
- the role of family in decision-making^{19,43,59}
- preferences regarding language used to discuss cancer¹⁵
- nonverbal communication standards¹⁵

Generic recommendation 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.

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^{14,15,50,63}
- Engage in culturally congruent communication which recognises that cultural variations exist between patient and healthcare professional and engages in culturally sensitive and competent communication accordingly^{14,61}
- Observe culturally appropriate nonverbal communication etiquette¹⁴
- Use congruent verbal and nonverbal communication^{14,61}

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

- Provide clear,^{58,61} accurate,^{58,61} open,^{47,48,54,64} flexible⁴⁷ and transparent⁵⁴ communication
- Provide information in the patient's language⁵⁸
- Learn the language⁵⁸
- Develop a vocabulary of terms familiar to the patient⁵⁸
- Include some basic isiZulu phrases in conversations¹⁸
- Use language that patients can understand¹⁸
- Use simple language^{18,41,46,48}
- Encourage the patient to ask questions^{18,45}
- Repeat information several times^{18,41}
- Check patient understanding of information^{18,41,49,56-58,63}
- Check what patients remember from previous explanations¹⁸
- Do not use medical jargon¹⁸

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

- Avoid stereotyping and generalisations^{14,19,38,42,55,57,58,61}
- Do not make assumptions about patient race, nationality and language^{15,19,21}
- Treat patients equally^{46,47}
- Encourage patients to raise concerns about discrimination⁴⁸
- Create a culturally safe and caring environment^{41,64}
- Individualise patient care^{42,64}

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

- Invest time in the beginning^{43,57,65}
- Engage the patient⁶¹
- Build rapport^{41,45}
- Gain patient trust^{32,45,47,50,61}
- Respond to patients' emotions¹⁸⁻²¹
- Actively engage patients in decision-making^{19,45,57,63}
- Encourage and empower patients to raise trust issues⁴⁸
- Address patients according to cultural preference⁶¹
- Recognise inherent power differentials⁶¹
- Be open about own cultural frame of reference⁴⁹
- Acknowledge own cultural background to patients¹⁵
- Respond skilfully to cultural discordance⁶¹

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

- Assess patients' specific communication needs⁶⁵
- Conduct a cultural assessment by actively exploring patients' culture^{54,56,65}
- Invite patients to describe their cultural backgrounds⁶²
- Explore views on family and community in the healthcare context⁶²
- Explore cultural⁶¹ and health beliefs⁵³
- Explore family expectations, feelings and concerns⁵⁴
- Explore level of family involvement required⁵³
- Determine who the main decision-makers are (patient or family?)^{19,21,42,43}
- Explore preferences for truth disclosure^{15,53,57}
- Explore patients' spiritual and religious beliefs^{15,54}
- Ask patients about their disease process^{19,20}
- Use Kleinman's eight questions^{32,62}

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

- Invest in and gain family trust^{46,61}
- Communicate with extended family as per patient's directive^{19,61}
- Afford the family maximum control possible if this is a patient need⁵⁴

It is recommended that healthcare providers instil and maintain hope regardless of the disease stage by:¹⁸

- Emphasising what can be done
- Informing patients that a palliative amputation could help with pain management
- Reassuring patients of continued involvement of the multi-disciplinary 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

Generic recommendation 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 illness⁴²
- Take responsibility for combating discrimination in healthcare settings⁴²
- Take responsibility for learning about the Zulu culture¹⁸
- Be willing to learn from patients⁶¹
- Be open to change and growth⁶⁴
- Be culturally sensitive^{15,42,64}
- Be willing to listen⁶⁴
- Develop and demonstrate respect for cultural diversity, for the patient's culture and their cultural values^{15,42,47,48,53,59-61}
- Demonstrate respect for patients' spiritual and religious beliefs⁴⁶
- Develop an appreciation of different health belief systems⁶⁰
- Be willing to explore culture with individual patients⁵⁷
- Validate different cultures⁶²
- Engage in continual self-examination and self-reflection to examine one's own values and assumptions^{52,55,64}
- Be willing to adjust behaviours and attitudes⁵⁷
- Reflect on own interaction with cultural groups in the clinical setting⁵⁷

Generic recommendation 5: Culturally competent healthcare systems

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

It is recommended that healthcare systems cultivate the following characteristics:

- Respond to individual needs and to how cultures are perceived^{50,55}
- Promote and facilitate effective patient-centred communication⁵⁵
- Respect cultural differences, and support effective care for diverse populations⁵⁴
- Provide ethnic-specific services¹⁴
- Convert an awareness of disease prevalence into practices and policies³⁸
- Develop and implement policies to support effective cross-cultural communication^{55,64}
- Link with culturally competent agencies and community organisations that provide bilingual and bi-cultural navigation, promotions and community health outreach services¹⁴

- Have adequate support services⁶⁴
- Include traditional healers in patient care¹⁹

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

- Use patient navigators^{36,43,45,61,66,67}
- Use experienced and professional interpreters^{14,15,32,42,45,48,49,53,58,62}
- Use culturally sensitive print, visual and audio-visual media and electronic communication^{45,49,63}
- Use images to assist providers when discussing cancer with patients^{18,41}
- Monitor patient characteristics⁴⁸
- Translate written communications⁴²
- Provide language-concordant encounters⁴⁸
- Provide patient-centred care⁶⁶
- Consult communities on cultural needs⁴¹
- Integrate community resources into cancer care¹⁴
- Display images of people from cultural groups attending the service⁴¹
- Have ethnically similar staff visible⁴¹

Specific 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.

Specific recommendations 1: 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.^{1-4,68} 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 complicate the diagnosis discussion especially when a good prognosis is possible. The isiZulu word for cancer is umdlavuzo 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 Zulu patients therefore requires an understanding of cultural and health beliefs and incorporating this knowledge into diagnostic conversations.

It is recommended that healthcare providers provide patients with factual information about their condition including:²¹

- Its name
- Prevalence
- Causes

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

- Starting the diagnosis discussion right from the beginning¹⁸
- Assessing how much the patient knows¹⁸
- Warning patients a few times about a possible cancer diagnosis^{18,21}
- Giving patients incremental information as the diagnostic process unfolds¹⁸
- Informing patients of the reasons for diagnostic tests^{18,21}
- Warning patients before delivering bad news when the diagnosis is confirmed^{18,21}
- Warning patients by reminding them of earlier conversations of possible diagnosis¹⁸
- Checking patients' readiness to receive the diagnosis²¹
- Offering privacy when communicating the diagnosis²¹
- Confirming diagnosis only once patient has been warned^{18,21}

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

- Building a relationship with the Zulu patient¹⁸
- Spending time with the patient¹⁸
- Offering the patient support¹⁸
- Demonstrating a personal interest in the patient¹⁸
- Assessing and addressing patient needs, emotions, and coping^{18,21}
- Responding to patient questions about the diagnosis¹⁸
- Assessing patients' reactions to the diagnosis¹⁸
- Responding appropriately to patients' reactions to the diagnosis¹⁸
- Managing the response of denial by¹⁸
 - 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 diagnosis¹⁸

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

- Taking responsibility for improving communication¹⁸
- Demonstrating an understanding of Zulu cultural health beliefs¹⁸
- Reassuring patients that their diagnosis is:¹⁸
 - not due to anything that they have done
 - not a punishment
 - not due to bewitchment
- Demonstrating a genuine interest in the Zulu culture by:¹⁸
 - Asking patients questions about
 - 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 discordance¹⁸

It is recommended that healthcare providers facilitate understanding of the diagnosis by:¹⁸

- 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

Specific recommendation 2: 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,¹⁷ treatment options are limited, and prognoses are often poor. Healthcare providers consequently must simultaneously inform patients of the diagnosis of osteosarcoma as well as the significant limitations regarding treatment options. Several cultural factors have been identified about 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.

It is recommended that healthcare providers provide patients with factual information pertaining to:^{19,21}

- 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)

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

- Delay providing treatment information until staging investigations are completed¹⁹
- Inform patients about the prognostic consequences of not treating the tumour, e.g. metastases, shortened life-span^{19,21}
- Balance hope and honesty¹⁹ by:
 - Communicating the urgency of intervening²¹
 - Offering patients reassurance²¹
- Ensure patient understanding by:¹⁹
 - Using analogies
 - Using the stages of cancer to explain disease progression and realistic treatment options
- Explore and manage patients' emotions associated with amputation and chemotherapy²¹

It is recommended that healthcare providers use these strategies for responding to cultural factors associated with amputation:¹⁹

- Time the treatment discussion to prevent the patient from signing refusal of hospital treatment before diagnostic testing is complete
- When patients refuse amputation, offer patients other treatment options such as 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 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

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-making¹⁹
- Demonstrate an understanding of patients' cultural beliefs by:
 - Acknowledging patients' need to discuss treatment with their family¹⁹
 - Encouraging patients to engage in their cultural traditions and rituals¹⁹
 - Encouraging patients to combine Western and traditional approaches^{19,21}
 - Respecting patients' cultural health beliefs and their desire to consult a traditional healer^{19,21}
- Liaise directly with family and cultural decision-makers where possible¹⁹
- Negotiate with patients to not go home and to rather invite a family member(s) to the hospital¹⁹

Specific recommendation 3: Strategies for communicating prognostic information pertaining to osteosarcoma with Zulu patients

Evidence-based rationale: Given the late presentation of patients at the study site, healthcare providers must 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.

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

- Enquiring about patients' thoughts, fears and impressions of the future²⁰

It is recommended that healthcare providers inform patients of the prognostic consequences of not treating the osteosarcoma:^{20,21}

- Inform patients of the likelihood of metastases if the osteosarcoma is not treated
- Inform patients of the effect on survival if the osteosarcoma is not treated

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 curable²⁰
- Inform patients that even with surgery the cancer could recur^{20,21}
- Inform patients that they must return within six months and then annually to check for cancer recurrence^{20,21}

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

- They have metastases^{20,21}
- The condition is not curable, but that amputation could help with pain²⁰
- Treatment options are limited due to the metastases²⁰

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 time²⁰
- Normalise death²⁰
- Do not inform patients of the life expectancy²⁰

It is recommended that healthcare providers use a staged approach to communicating about prognosis.²⁰ 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.

Conclusion

Communicating with patients about cancer in cross-cultural clinical settings is widely recognised as a challenging task. This guideline offers guidance about approaching this daunting task. The limitations of the body of evidence are noted and should be considered when this guideline is reviewed. Some of these limitations include the mostly low-level evidence (Level 5) 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 thereby limiting the size of the sample. This guideline included research with the healthcare providers and patients thus providing higher levels of evidence for some of the recommendations. Further development of this guideline needs to address the remaining limitations. Furthermore, 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 also facilitate further development of the guideline.

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Ethics statement

The authors declare that this submission is in accordance with the principles laid down by the Responsible Research Publication Position Statements as developed at the 2nd World Conference on Research Integrity in Singapore, 2010.

Prior to commencement of the study ethics approval for the PhD study was obtained from the Biomedical Research Ethics Committee (BREC) of the University of KwaZulu-Natal (UKZN) (reference no: BE051/15) where the PhD study was registered. This guideline refers to findings obtained from studies with healthcare providers and patients done as part of the PhD study. Informed consent was always obtained from both these groups in a language that was preferable to the participants, namely English or isiZulu.

All procedures were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2008.

Declaration

The authors declare authorship of this article and that they have followed sound scientific research practice. This research is original and does not transgress plagiarism policies.

Author contributions

OB 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.

RMvR 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.

CA 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.

LCM 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.

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