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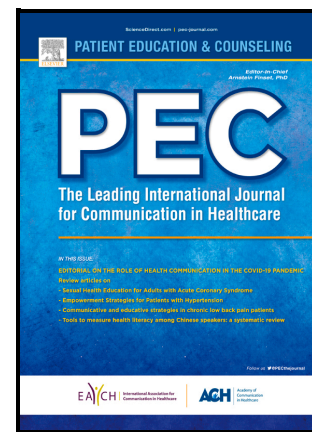
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# Journal Pre-proof

Breaking bad news in a cross-language context; a qualitative study to develop a set of culturally and linguistically appropriate phrases and techniques with Zulu speaking cancer patients

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Title:

Breaking bad news in a cross-language context; a qualitative study to develop a set of culturally and linguistically appropriate phrases and techniques with Zulu speaking cancer patients

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CRedit author statement

Louise Walker: conceptualization, methodology, formal analysis, writing – original draft, writing – review & editing

Stephanie Sivell: supervision, writing – review & editing

Abstract

**Objective:** Breaking bad news (BBN) in healthcare is common. Guidelines abound but little is documented in an African context. We wanted to describe Zulu speaking patients' BBN experience and assess their opinions of internationally recommended techniques.

**Methods:** BBN techniques were highlighted from the literature using systematic review methods. Semi-structured focus group interviews with Zulu speaking cancer patients were conducted. Data were analysed using Framework Analysis.

Results: Language concordance was central – regardless of whether this necessitated a nurse acting as translator. While non-abandonment, empathy and maintenance of hope was valued by participants, an oft-expressed belief in positive outcomes accounted for mixed responses to phrases implying ambiguity. In contrast, “I wish” phrases were appreciated. Silence received mixed responses with a strong dislike for silence as a front for non-disclosure.

Conclusion: Language-related concerns dictated the bulk of participants BBN perspectives. While cultural and linguistic differences exist, good communication skills, empathy and the maintenance of hope remain central.

Practice Implications: BBN in a language in which the patient is fluent, whether mediated or not, should be the standard of care. Cultural and linguistic variance must be born in mind and clinicians should become familiar with the preferences of the communities they serve.

Keywords: breaking bad news; Cancer diagnosis; Zulu; cross-language communication; crosscultural communication

## 1. Introduction

Breaking bad news (BBN) is commonly encountered in healthcare. Bad news was defined as “any information which adversely and seriously affects an individual’s view of his or her future” [1,2]. This study aimed to assess experiences and opinions of Zulu speaking cancer patients regarding BBN to guide doctors when faced with cross-language BBN.

Cross-cultural communication in healthcare is common and appropriate skills are needed as population patterns change [3–5]. Culturally competent care is imperative [6,7]. International BBN guidelines abound with some for specific contexts or cultural groups [8–10]. Despite this, literature focusing on African cultures or languages is sparse.

Zulu, the most common home language in South Africa [11], is an indigenous African language of the Bantu group (Nguni subgroup) spoken mostly in KwaZulu Natal [12]. Zulu is not the dominant language of the healthcare system with many practitioners and training institutions using English. As a result, cross-language communication in South African healthcare is common: over 80% of healthcare interactions take place across language barriers [7]. Professional interpreters are lacking [7,13] and the onus is on clinical staff to ensure patients understand discussions.

While BBN may be demanding and often uncomfortable for practitioner and patient [14,15], it is generally accepted that bad news should be disclosed to the extent that the patient wishes [14,16]. BBN techniques have repercussions for all involved [17–19]. Many authors posit that communication is an important clinical skill [20–24]]. In this study, we aimed to discover how Zulu speaking cancer patients experience BBN, what factors were important and how internationally recommended techniques could be used with this population. This study reflects experiences and desires of patients from non-English speaking communities in

a predominantly English healthcare system. Practitioners are hereby sensitized to the needs of different cultural and language groups.

## 2. Methods

**Aims:** describe challenges associated with cross-language BBN as well as non-English speakers' opinions of internationally recommended phrases and techniques, with specific focus on Zulu speaking cancer patients.

**Objectives:** describe the BBN experience of Zulu speaking patients; identify pertinent internationally recommended BBN phrases and techniques; elicit opinions from Zulu speakers of translated versions of these phrases.

### 2.1 Approach

Semi-structured focus group interviews were held with Zulu-speaking cancer patients; the number of focus groups was decided a priori in accordance with the literature [25,26]. Individual interviews were included in the protocol but ultimately only used for the pilot interview. Qualitative data were analysed using Framework Analysis (FA). Ethical approval was from the Umgungundlovu Health Ethics Review Board (UHERB 180101) and written informed consent obtained from participants.

### 2.2 Sampling and recruitment

Homogenous, purposive sampling was used. Inclusion criteria were treatment with radiotherapy for a cancer diagnosis, age over 18 years. To recruit patients within a short period after diagnosis was challenging due to local referral patterns. Participants self-identified as Zulu first/home language speakers.

### 2.3 Development of the interview guide

The interview guide was developed a priori based on the literature and comprised of two sections. The first section reviewed participants' BBN experience and the second elicited opinions on phrases and techniques from international literature. A full systematic review was not feasible but systematic review methodologies were used on Medline (Ovid platform), PsycINFO, CINAHL and Embase databases. Article reference lists, "related articles" sidebars, expert suggestion [27] and the first 100 hits on Google Scholar [28] were reviewed. The Medical Subject Headings (MeSH) search string for the Medline database is detailed (figure 2.1). To pinpoint key phrases and techniques for clinical use is challenging therefore a thematic approach to selection was undertaken. The interview guide was updated in an iterative manner by the principal investigator (LSW). The interview guide is included as supplementary material.

### 2.4 Data collection

Discussions were conducted in Zulu by LSW and the study translator. LSW is a medical doctor in a publicly funded oncology clinic and has a functional understanding of clinical Zulu. The study translator studied Zulu at tertiary level and has in-depth understanding of

Zulu language and culture. He was not involved in healthcare. Discussions were audio-recorded, anonymously transcribed and translated into English. Field notes were made by LSW and unrecorded debriefing sessions were held between LSW and the study translator. The work was part of a Master of Science (MSc) degree in Palliative Medicine undertaken by LSW and supervised by SS. SS reviewed each stage of the project and provided guidance on analysis.

## 2.5 Data analysis

FA is a method of thematic analysis where the key feature is the use of a matrix-based approach to qualitative analysis [29].

There are five key stages to FA [29–33]:

1. Familiarisation with data.
2. Creation of a framework for data analysis.
3. Indexing of data where the framework is applied and concepts are labelled accordingly.
4. The creation of a matrix of themes (columns) and cases (rows). This is the definitive step of FA.
5. Mapping and interpreting data.

FA provided structure to the analytic process through a priori development of a framework but was flexible enough to accommodate emergent themes [29]. The matrix ensured an explicit audit trail [31,34], improving the credibility and confirmability of findings [35]: an important consideration due to limited prior research in this field. FA identified nuances in individual BBN experiences despite group discussions [35]. Transcripts were coded in MS Word and the FA matrix created in MS Excel [34,36]. Efforts were made to retain context throughout the analytic process.

## 2.6 Cross-language research-related issues

The interview guide was developed in English and translated into Zulu. The pilot interview was in English but all focus group discussions were in Zulu due to participant preference. Study documentation was available in English and Zulu. Data were analysed in English. The study translator translated all documents, conducted the interviews and transcribed and translated the discussions. He also reviewed results after analysis to ensure accuracy and was remunerated.

## 3. Results

### 3.1 Phrases and techniques from international literature:

The literature review included articles published from 1995 to December 2017. The following phrases and techniques were identified:

- Silence [37–41].

- “I wish” statements [38,41–47].
- Empathic phrases like “I understand this must be difficult for you to hear” [39,44,45,48,49].
- “I’m sorry” statements [22,40,47,48,50].
- Avoidance of nihilistic statements (“there’s nothing more we can do”) [48,50,51] and statements of realistic non-abandonment (“anything I can do to help”) [47,50].

### 3.2 Results of focus group discussions:

Four focus groups were held between May and August 2018 with 29 participants. Diagnoses reflected clinical practice at the study centre. Most participants were female (2,6 females to every male participant). Ages ranged from 21 – 80 years with a median of 54 years. Detailed demographic and diagnostic data are in table 3.2 and figure 3.1.

Discussions were grouped into two overarching themes:

1. The bad news experience
2. Responses to phrases and techniques.

#### 3.2.2 The bad news experience

Seven key sub-themes emerged, detailed in figure 3.2.

##### 3.2.2.1 Positive and negative BBN experiences

Participants’ BBN experience ranged from positive through neutral to negative. The doctor’s language choice was important. Similarly, a Zulu interpreter when the doctor spoke English was valued.

“I welcomed being explained to, in my own language... I couldn’t understand the doctor but a translator came and translated for me, I was able to understand what [the doctor] was saying.”

Participant 2, focus group 3.

It was felt that if BBN was in Zulu, it was of no consequence whether this required the assistance of an interpreter.

A positive BBN experience was not purely language-related but included assurances of assistance from doctors. Negative BBN experiences involved being uninformed about the diagnosis, not understanding what was said and being dissatisfied with the manner of disclosure. Problems understanding were due to language used (i.e. English) and to complexity of the topics discussed, regardless of language.

“...because even in Zulu we might not understand each other... that’s a problem.”

Participant 2, focus group 2.

Disclosure of the bad news was desired by all but one participant, who preferred family be told.

“No, he/she should just phone my home and apologise, saying he/she won’t be able to help me anymore. Then I should go home.”

Participant 1, focus group 1.

Not all problematic BBN experiences were language-related. Hurried consultations and lack of explanations were unpopular. Participants in focus group 1 disliked being talked about by a group of doctors but excluded from the discussion. This is highly insulting in Zulu culture.

“Obviously if the doctors are chatting amongst themselves, I wouldn’t get a chance to talk, I’d take my file and leave. ... Because I don’t hear what they say, they talk amongst themselves.”

Participant 2, focus group 1.

Thus, while the majority of negative or positive experiences involved language-related concerns, some participants were distressed by the manner of the consultation.

It is notable that some participants assumed BBN to have gone well due to lack of experience with BBN, expressing a positive bias towards doctors’ behaviour.

“He/she did it in the right way, because I didn’t know of any better way, but he/she did it in the right way.”

Participant 2, focus group 3.

### 3.2.2.2 Intangible concepts associated with BBN

The role of intangible concepts classified as hope and fate/destiny was discussed by each focus group. Maintenance of hope was felt to be central. Doctors’ assistance and treatment were felt to promote hope. Losing hope was expressed as tantamount to dying.

“If the doctor says there’s no hope for me, I’d take my bags, go out the gate and go and pass away at home.”

Participant 4, focus group 1.

An unexpected but important finding was summarised as fate/destiny: the belief that should treatment be properly undertaken then outcomes would necessarily be good. The potential for treatment not to be successful was not considered by many and difficult to explain.



“It can be cured, the cancer, if you follow your treatment at the right time. If you’re called saying ‘you’re needed here’, you should accept that and come. And you will be healed if you keep to the treatment.”

Participant 2, focus group 3.

Faith in a higher power was often mentioned as an important coping mechanism and facilitated a positive outcome.

“but you should pray to the creator and be in the mind-set of ‘I might live, I might not.’ As you know, we all have our time to live on this earth, if you have cancer or not.”

Participant 2, focus group 3.

### 3.2.2.3 Staff involved in BBN

Both doctors and nurses played roles in BBN. No other healthcare workers or interpreters were mentioned. Doctors had several roles: purveyor of knowledge, source of hope and infallible expert. One participant noted the potential for doctors to be intimidating.

“He/she should give me hope saying: because you’re here and we’re treating you, you will get better.”

Participant 3, focus group 4.

The main role of the nurse was to facilitate understanding – often as interpreter. He/she also acted as a cultural broker. Generally, the involvement of a nurse was positive although some participants were concerned about fidelity when interpreting. Nurses were felt to be approachable and duty-bound to care for patients.

“Yes, and I’m not educated, I don’t understand what they [the doctors] say. The nurses need to help me.”

Participant 6, focus group 1.

### 3.2.2.4 Suggestions to improve BBN

Language-concordance (either with a translator or a Zulu-speaking doctor) played a central role in good BBN. Other suggestions included active listening and a positive outlook. Willingness to attempt therapy and information transfer were important.

“We need to listen to each other, that he/she listens so that I can also listen and understand”

Participant 1, focus group 1.

Not all responsibility for successful BBN lay with the doctor: many participants felt they should ask questions and clarify issues. The opportunity to ask questions was not unanimously positive due to self-perceived lack of competency.

“I think that the doctor should just tell me, I don’t think I’ll be able to ask my own questions because I might not understand how it will all go. Yes, he/she should tell me how it is and I might accept it all a bit better.”

Participant 2, focus group 4.

Support from relatives and other patients was important to a minority of participants.

“But you need to have people who support you... Especially with this cancer that we are diagnosed with, ... and because we’re a group, we are able to tell someone new to being troubled by cancer, who might be scared, and we’re here for them...”

Participant 1, focus group 1.

### 3.2.2.5 Participant reactions to bad news

Responses to BBN can be regarded as a single dimensional typology, illustrated in figure 3.3, varying from fearful or shocked through upset/worried to unaffected then comforted and optimistic. It is likely that people will move through different aspects of this typology as they deal with BBN.

“He/she then said the thing he/she saw was, that there’s a cancer. That comforted me.”

Participant 5, focus group 2.

### 3.2.3 Responses to phrases and techniques

The different sub-themes of this theme (silence, “I’m sorry”, “anything I can do to help”, “I’m worried”, “I hope” and “I wish”) may be reviewed using negative, positive or neutral responses. A treemap of these sub-themes (figure 3.4) depicts this.

#### 3.2.3.1 Silence

Silence elicited many responses and caused controversy. Silence had negative, positive and neutral connotations – illustrated in figure 3.4.

“That’s good if the doctor [is quiet for a bit]. Then you could ask how it would go from there, and he/she would explain to you.”

Participant 1, focus group 2.

Silence facilitated further explanations but could be a delaying tactic. It was strongly felt that silence should not be a guise for non-disclosure.

“[Silence] means for me that the doctor didn’t want to give me this news, that he/she was scared to tell me.”

Participant 3, focus group 4.

Discussion regarding the duration of silence occurred in all focus groups with an overwhelming sense that silence should not be long. Doctors were felt to use silence to assess patients’ reactions and to minimise fear.

“I think that the doctor would do this so that you wouldn’t get too scared... He/she’d do that so that you would accept the news in the right way.”

Participant 5, focus group 4.

One participant felt doctors may use silence to signify transference of responsibility for discussion from doctor to patient.

“He/she’s just told you that you have a problem, that you have cancer. He/she should keep quiet but he/she’s done his/her work, so now it’s up to you if you want to ask questions, as in ‘how should I go forward?’.”

Participant 2, focus group 3.

### 3.2.3.2. “I’m sorry”

Empathic responses, summarised as “I’m sorry” were also debated: some participants felt negatively as they may result in loss of hope. Conversely, some patients appreciated such statements.

“I welcome it if the doctor says they’re sorry, because it means that they’re thinking that the words they are speaking to me might affect me badly...”

Participant 3, focus group 4.

Several participants felt “I’m sorry” shifted focus from the patient to the doctor, with many patients expressing concern for how the doctor felt.

“You see that if the doctor’s spoken and my spirit is down, he/she’s wishing that that which he/she spoke about could pass”

Participant 5, focus group 4.

Empathy as a concept was broadly beneficial, regardless of how it was expressed. Focus group four particularly valued this concept, noting empathy in “I’m sorry”, “I hope”, “I’m worried” and non-abandonment phrases.

### 3.2.3.3. “All I can do to help”

Statements of non-abandonment were unanimously appreciated and supported as a comfort and increasing hope. Furthermore, participants trusted these statements.

“That would make you happy. He/she’ll do everything in her power to help you, that would make you happy... even if he/she sees that the disease has gone into different places but he/she will try to help you. That makes me happy.”

Participant 3, focus group 3.

### 3.2.3.4. “I’m worried”

Phrases prefaced with “I’m worried” received mixed responses. Some participants felt this phrase diminished hope, others felt it was useful and expressed empathy. Still others felt it reflected doctors’ feelings of fear or unhappiness.

“He/she doesn’t give you much hope anymore, but he/she’s trying for me but hasn’t succeeded. And he/she’s scared to say ‘I’ve not come right’.”

Participant 1, focus group 1.

As explored in 3.2.2.2., participants’ preference for certainty when speaking of positive outcomes was striking. The possibility of failure of treatment was not something easily or often acknowledged.

### 3.2.3.5. “I hope”

As per figure 3.4, phrases using “I hope” were largely, but not exclusively, positively received. All participants prized hope as this bolstered their own hope. However, others preferred doctors to speak with more certainty.

“He/she shouldn’t say ‘I hope’, he/she should say ‘you will be well’.”

Participant 3, focus group 1.

### 3.2.3.6. “I wish”

This was the preface that invited the least discussion: all comments on this phrase were positive.

“I feel comforted by ‘I wish’, because it’s like it can end, like it can be healed, this cancer that’s troubling me, you see? Yes, I would really like them to stay inside me [the words].”

Participant 2, focus group 4.

“I wish” phrases signified a common purpose— an impression that was echoed by “I hope” and “anything I can do to help”.

### 3.3 Summary

The salient finding was the importance of language-concordance in a BBN scenario – although whether this was with an interpreter or not was not considered important. Disclosure of bad news was strongly preferred. Participants reported mixed experiences of BBN but were generally satisfied with only minor concerns. Staff involved were doctors and nurses. Patients' trust and belief in treatment success was surprising and echoed by mixed responses to statements implying uncertainty like "I hope" or "I am worried". Statements implying solidarity and empathy were well received and "I wish" statements were unanimously popular.

## 4. Discussion and conclusion

### 4.1 Discussion

This project identified, translated and solicited opinions on phrases from international BBN guidance for use with Zulu-speaking patients. While responses were heterogeneous, it provided insight when adapting international best-practice for local settings and highlighted the importance of individualised BBN [21,52]. Zulu patients experience BBN through a range of responses (figure 3.3) rather than as a discrete event, echoing the international literature [21,52]. In contrast to some international studies [51,53,54], participants seemed satisfied with BBN in three of the four focus groups. Participants' inclination towards satisfaction with BBN due to inexperience in such situations was not echoed in the international literature.

Lack of concern about working with an interpreter was striking. There was an overwhelming impression that Zulu was spoken, it did not matter whether the doctor was speaking Zulu or an interpreter was used. While there was concern about misinterpretation, it seemed that the patient-doctor relationship was enhanced rather than jeopardised by an interpreter. It must be noted that the interpreter was always a nurse. No participant mentioned a professional interpreter or family members assisting. The nurses in question were first-language Zulu speakers trained in an English-language system [13]. When combined with nurses' traditional role of patient-support, this presents a potentially powerful dynamic: an ad hoc interpreter with a medical background and a professional duty of care. To my knowledge, this is not discussed elsewhere and warrants further study.

Dissatisfaction with doctors using jargon [55] was echoed by Zulu speaking patients expressing confusion with complicated concepts. Similarly, preference for information disclosure is found in recent literature [52,56,57]. It is noted that disclosure to relatives is favoured by a minority of patients – both in this cohort and in the literature [6,58]. This necessitates tailoring BBN to individual patients: a common feature of many communication guidelines [6,8,9,14,38,59–64].

Hope was central to patients' discourse and doctors were felt to have a key role. This concurs with the international literature [7,65]. An unexpected finding was the strong belief in positive outcomes of treatment. It is important that doctors counselling Zulu speaking patients take cognisance of this fact although further study is required. Empathy in any

form was positive and often the reason a certain phrase or behaviour was appreciated. The use of empathic phrases in other languages and cultures is more complex than simply translating words. This was highlighted by the mixed responses to phrases prefaced with “I’m sorry”. Quill, Arnold and Platt [66] discuss potential problems with these phrases including changing focus of the conversation from patient to doctor – something echoed in this study. Statements of non-abandonment were considered to express empathy and much liked. It must be remembered that this needs to be realistic and consider local resource constraints [47,67]. Participants in this cohort trusted doctors regarding non-abandonment, reinforcing the need to create only realistic expectations.

In comparison to “I hope”, the unanimously positive responses to “I wish” showed solidarity and support where “I hope” implied a possibility of lack of success. While “I hope” was not necessarily the phrase of choice for participants, it may be a useful when implying both solidarity and a lack of certainty regarding outcomes. Silence received decidedly mixed responses despite frequent recommendations in the BBN literature [37,38,40,52,68]. The suspicion of silence as a guise for non-disclosure was a new finding and reflects preference for information sharing.

#### 4.1.1 Strengths and limitations

While many articles address BBN with cancer patients and others review cross-language consultations, this study uniquely addresses both simultaneously while focusing on Zulu speakers. A study hallmark is its cross-language nature. This was unavoidable and justified by benefitting an under-researched population. It is important to note that cultural beliefs and practices were not analysed. The study translator was not medical and this balanced the LSW’s role as a clinician. The proficiency of the study translator and collaboration between study translator and LSW allowed for contextual accuracy rather than a literal translation [69].

Careful analysis of translated transcripts avoided loss of fidelity due to translation through attention to field notes and review of provisional results by the study translator. The narrow focus on Zulu speakers allowed for rich data collection in an under-researched field. This may limit transferability of specific findings but general lessons (e.g. the importance of language choice when BBN) is of relevance in a broader context.

The relatively small number of focus groups allowed detailed data analysis. It may also mean quieter participants were reluctant to voice opinions. Care was taken during discussions to minimise this but particularly patients with head and neck cancers found participation difficult. Individual interviews, potentially negating this, were offered but declined by all participants. It is important to note the delay between the BBN experience (i.e. the cancer diagnosis) and study recruitment; this was unavoidable due to delays in referral and treatment commonly experienced in this setting. Participants had a range of literacy levels, as is typical in our patient population [70] and those with low literacy were deliberately included although it was not feasible to actively control for or measure literacy. Participants were treated with radical intent – this limited the details of the BBN experience.

#### 4.2 Conclusion

BBN in a language appropriate for the patient, ideally their home language, is crucial. Whether this is achieved by a doctor speaking the patient's language or with an interpreter was of minimal importance. Empathy and solidarity were important elements of well conducted BBN; difficulty lies in how these concepts may be conveyed. Commonly advocated techniques like silence and "I hope" or "I'm worried" may be misinterpreted by Zulu speaking patients while "I wish" phrases and phrases of non-abandonment are well received.

#### 4.3 Practice Implications

Conducting BBN in a language the patient understands – with or without an interpreter should be the standard of care. Variation exists in the interpretation of phrases commonly advocated for use when BBN. It is beneficial for clinicians to reflect on patient populations and develop phrases preferred by the communities they serve. It is important to remember beliefs commonly held by community members, like the perception of treatment success held by many Zulu speaking patients.

Tables and figures

Fig 2.1 MeSH search string

Fig 2.1 MeSH search string

1. Breaking bad news.mp OR truth disclosure/ OR disclosure/  
AND
2. Palliative medicine/ OR palliative care/ OR terminal care/  
OR neoplasm/ OR hospice care/

Table 3.1 Participant ages

	Age (years)
Minimum	21
Maximum	80
Mean	55
Median	54

Table 3.2 Participant time from diagnosis to participation

	Time (months)
Minimum	4.5
Maximum	37
Mean	12.0
Median	11.6

Figure 3.1 Participant diagnoses

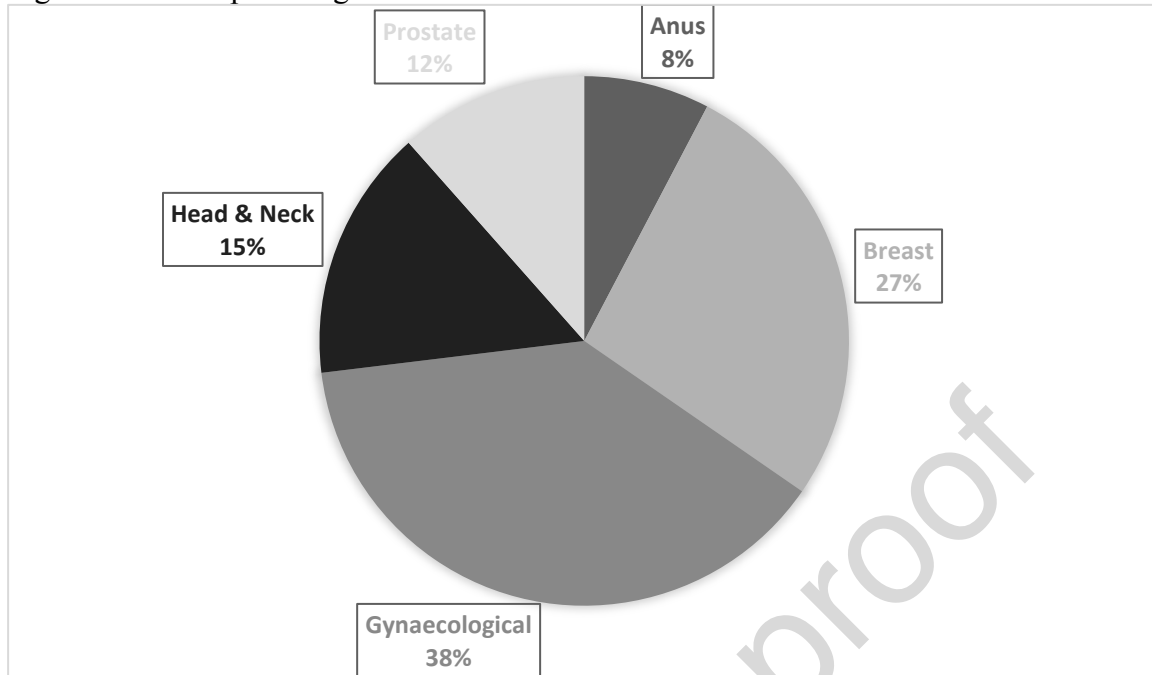


Figure 3.2 Key sub-themes in the bad news experience

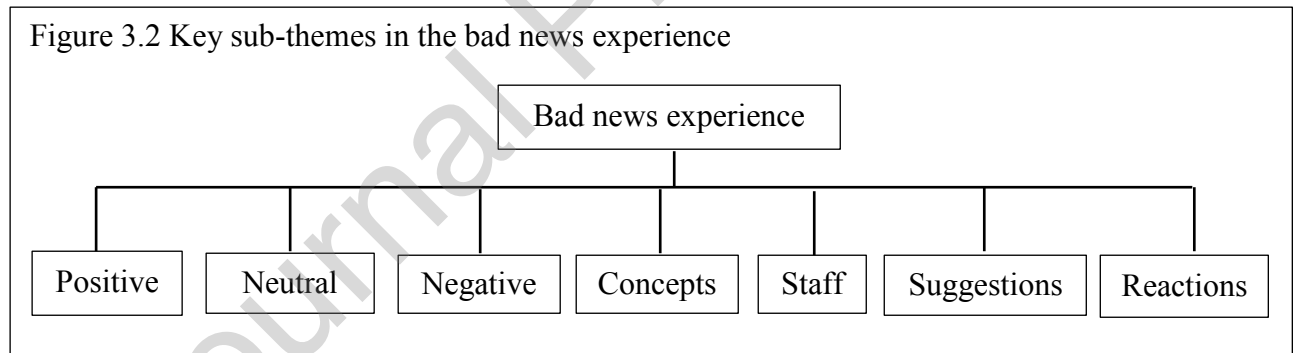


Figure 3.3 Single dimensional typology of participant responses to bad news

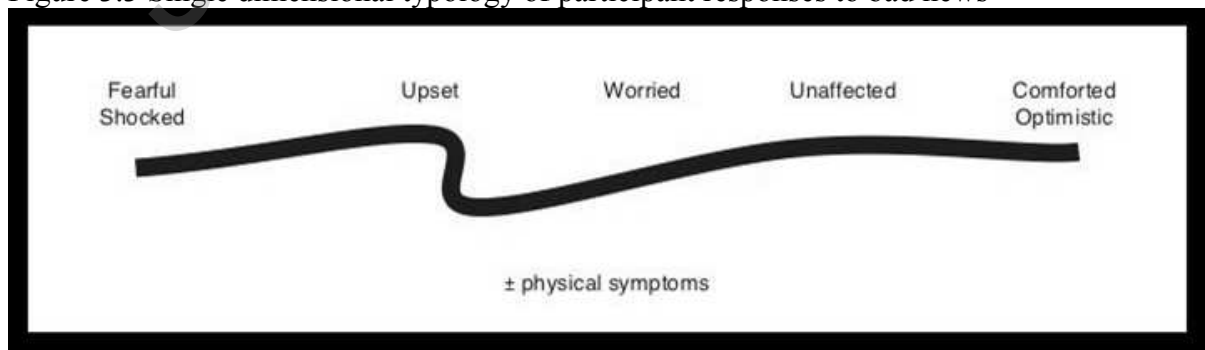
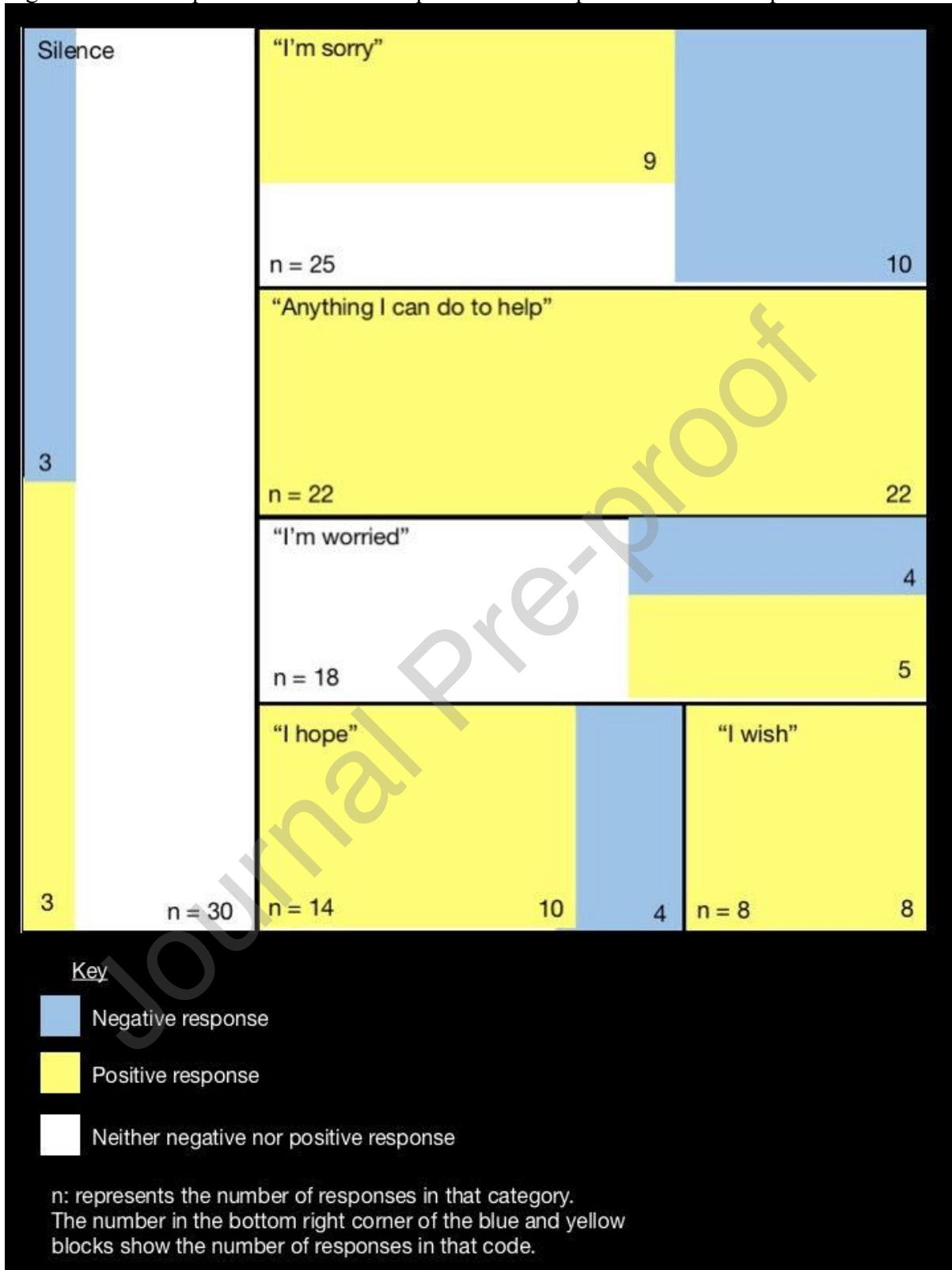




Figure 3.4 Treemap of sub-themes in responses to BBN phrases and techniques



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### Declaration of interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

### Highlights

- Breaking bad news is complex and needs to be individualised.
- This should be in the patient's language, whether interpreted or not was insignificant.
- Care is needed when adapting guidelines: implications differ once translated.
- Cultural groups differ in preference for recommended phrases.