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# BMJ Open Breaking bad news in oncology practice: experience and challenges of oncology health professionals in Ethiopia - an exploratory qualitative study

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#### **ABSTRACT**

**Objective** To explore the experience and challenges health professionals face during breaking bad news (BBN) to patients with cancer in the oncology centre of Black Lion Specialized Hospital (BLSH), Addis Ababa, Ethiopia 2019.

**Design** An exploratory qualitative phenominological study using in-depth interviews was carried out in the only radiotherapy integrated oncology centre in Ethiopia during March 2019. Purposeful maximum variation sampling was used to select participants. OpenCode (V.4.02) assisted thematic analysis approach was employed to analyse the

Participants Eleven oncology health practitioners (oncologists, residents and nurses) working at the oncology centre were interviewed. Repeated interviews and analysis were done until theoretical saturation. **Results** All participants were cognisant of the positive outcome of proper and effective practice of BBN. However, they were practicing it empirically, no standardised protocols or guidelines were in place. Four dimensions of challenges were mentioned: (1) setup centric: unconducive environment, lack of protocols or guidelines, inaccessible treatment, and psychotherapy or counselling services; (2) health care centric, such as inadequate expertise, inadequate time due to patient load, treatment backlog, and referral system: (3) patients/family centric; poor medical literacy level, poor compliance, and family interference; and (4) sociocultural: wrong perception of families on BBN and treatment modalities, and opposition from religious leaders.

**Conclusion** BBN is challenging for professionals caring for patients in the oncology centre of BLSH. Hence, there is a critical need to improve practices. Change efforts may focus on the development of contextualised, content and context specific practice oriented training programmes and curriculum interventions. Raising awareness of the community and religious leaders regarding the nature and treatment of cancer may also be a helpful adjunct.

#### INTRODUCTION

Bad news is any medical information that significantly and undesirably affects the attitude of a person toward their future. 1-3

#### STRENGTHS AND LIMITATIOS OF THIS STUDY

- ⇒ Addressed breaking bad news experiences in healthcare beyond diagnosis time.
- ⇒ Determined adequate sample size using purposeful maximum variation.
- ⇒ Only evaluated health professionals' perspectives. relying on self-reports.

Breaking Bad News (BBN) is the delivery of an emotional subject among healthcare professionals as patients' positive or negative experiences that can significantly affect their consequent adaptation. It is a process of interactions that take place pre, during and post breaking of bad news. 1 4 5 Despite its obvious importance, it is a difficult and unpleasant daily practice, especially for health professionals working in oncology.3 On the other hand, hiding information from patients prevents them from making proper therapeutic decisions based on their personal goals. In the present day, treatment advancement changes the progressions of cancer, and it is much easier to offer patients hope than the past time at the time of diagnosis. Still, it should be an important communication skill for many oncologists. BBN involves multiple interactions and care must be taken to prevent detrimental effects to a patient, family and their future relationships with bealthcare professionals. Both verbal components and soft skills are required. 467

In contemporary biomedical ethics, BBN of a serious medical condition, such as a new cancer diagnosis, is an important yet uneasy task for many health professionals.<sup>3 8</sup> The diagnosis and prognosis related information must be explicitly stated, understood and well-discussed in the most gentle and comfortable manner.<sup>8 9</sup> The accurate information being provided can help patients



make informed decisions about their treatment and take responsibility for their care and help them make appropriate plans for their future. 4 5 However, it is necessary for the therapeutic team to recognise the patients' social, psychological and clinical concerns, which helps to identify and evaluate the patients' absolute power and relative potential for handling the bad news and help establishing effective communication with patients and their families. Poor communication has been found to produce unfavourable physical and psychosocial outcomes, such as poor pain control, worse compliance to treatment and patient discontent. On the physician side, communication difficulties lead to job dissatisfaction and higher stress levels, affecting the doctor-patient relationship. It can also be leading cause of iatrogenicity and litigation against the health professionals and health facility. 45 10 11

Unlike other societies, in Western cultures there is a predominant belief that patients should have full disclosure of bad news if this is their wish. 45 Despite this cultural belief, health professionals encounter many challenges that hinder appropriate disclosure of bad news. These include doctor related barriers such as lack of formal training, time constraints, human failings, concerns about not upsetting the patient and language competence; and cultural barriers, such as being presented with unexpected questions, burnout and fatigue, deficiency of experience, spiritual and cultural believes, personal attitudes. Other barriers such as patient or relatives related barriers can impact the delivery of bad news-including differing needs of a diverse range of patients and relatives, patients' and relatives' diverse backgrounds, cultures, religions, languages, levels of intelligence and ages. Communication climate and statistical targets are the most common organisation related barriers.

A study conducted in Ethiopia to assess communication barriers between patients with cancer and physicians found that language barriers, inadequate time and lack of a private examination room were some of the main challenges. Although much is known about the experience and practice of BBN in the Western world, BBN in Africa is a poorly understood practice. There is limited information on the challenges and experience of cancer care providers including their understanding of practice standards of BBN. The current study is, therefore, designed to explore the typical experience and challenges of cancer care providers about BBN practice and inform possible interventions to improve BBN practices and avoid harms in the African context.

## **METHODS**

The authors used Standards for Reporting Qualitative Research checklist to ensure transparency and clear reporting of qualitative research methods and findings in preparing this manuscript (online supplemental file 1).

**Table 1** Description of the study participants, March 2019, Black Lion Specialized Hospital, oncology unit, Ethiopia

Study participants	Gender	Job titles
P1	Female	BSc Nurse
P2	Male	BSc Nurse
P3	Male	*R3
P4	Male	*R4
P5	Male	*R4 (senior)
P6	Male	*R4
P7	Male	Senior consultant
P8	Female	Oncology nurse (MSc)
P9	Female	Oncology nurse (MSc)
P10	Female	*R3
P11	Male	Senior consultant

P1-11, Particpant 1-11; R3, R4, Year three resident, year four resident .

#### Study setting and participants

The study was conducted at Black Lion Specialized Hospital (BLSH), oncology centre in Addis Ababa, Ethiopia, which is the only oncology referral centre in the country. It is a tertiary level teaching hospital under the college of health sciences of Addis Ababa University. The oncology centre provides diagnosis and treatment services to approximately 400 000 patients per year. The center employs more than five senior oncologists, thirty-nine residents, one general practitioner, seven oncology nurses, and twenty general nurses. The study was conducted in March 2019 at Ethiopia's leading and first oncology referral center.

A qualitative study using phenomenology study design<sup>13</sup> was conducted to explore the typical experiences and challenges of cancer care providers during BBN practice. Purposeful maximum variation sampling technique<sup>14</sup> was used to recruit study participants aiming to explore diverse views and rich experiences, therefore, to explore diverse views and rich experiences, therefore, various categories of oncology health professionals at different level of clinical experience from both sexes were represented. General nurses, oncology nurses, oncology residents and senior oncologists who were engaged a minimum of 2 years in clinical experience at the oncology centre were included in the study. In-depth interview was conducted with a total of 11 study participants/practitioners (2 oncologists, 5 oncology residents (year 3 and above), 2 oncology nurses and 2 general nurses) on their **2** experience and challenges of BBN practice. Moreover, information on sociodemographic characteristics of the respondents was collected from all participants. Interviews were conducted using semistructured interview guide which was developed for the research purpose. Notes on interviews were taken during the interview and yet tape recorded. Recruitment continued to the point of data saturation. Verbal consent was obtained for participation in the study (table 1).

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#### **Method of data collection**

Candidate participants were selected from a staff list of health professionals. If the practitioners agreed to participate (got verbal consent), an appointment for the faceto-face in-depth interview was set.

The interview guide was developed focusing on professionals/practitioners' typical experiences and challenges they encountered on BBN practice, suggested solutions and strategies to improve the effectiveness of BBN practice in oncology centre. And it was grounded on the objective of the study (online supplemental file 2).

All interviews were conducted in Amharic, the official language of Ethiopia, by the author TM. In addition to the interviews, notes were taken during the interview period by assistant researcher WH, and by TM on conditions where it is required to do so. Following the interview, notes were taken about the researcher's impression on the information generated from the interview and whether the interview provided an in-depth exploration of the phenomenon. This evaluation process was useful for the subsequent interviews to formulate further questions to clarify the topic. In addition, these notes reflected the researchers' feelings about the phenomenon and whether the interview provided similar or different perceptions and viewpoints.

Individual interviews are a widely used qualitative method for collecting data, allowing for in-depth insights into participants' perceptions, beliefs and personal experiences. 15 Mean interview length was 37.4 min (range: 17.51-67.17 min).

Except one study participant who was interviewed out of the oncology centre, all interviews were conducted in their clinical offices and privacy was assured for all interviews. No compensation was provided for participation.

## **Data analysis**

After completion of the interview, all the audio tape records were transcribed in verbatim and then translated into English again by TM. The data was coded by two independent coders (TM, WH) that helped to define themes in reference to the objectives, using OpenCode computer software V.4.02. Then, inter-coder verification was done to ensure that the codes were the reflection of the collected data. Codes were further categorised under themes and variations between the independent coders were discussed to reach at common themes. The themes were reviewed for validity, relevance and correct representativeness of what was contained within the data. Data analysis was undertaken simultaneously with data collection, considering the emerging themes and issues. At the end, two themes were identified: typical experience which was categorised into two subthemes as typical experiences on outcome of BBN disclosure and typical experience on ethical issues. Theme 2 is referred to challenges affecting BBN, which was also categorised into four subthemes as follows resource and organisational setup related, patient/ family related, professionals related and sociocultural and religious related challenges. In summary, suggested solutions

and strategies analysed in one section. A thematic analysis 16 17 with inductive approach was employed to analyse

#### Validation of analysis

Concerning the trustworthiness of the study, the investigator proceeded to actions aiming to enhance credibility, transferability, dependance,

A detailed and clear information were provided to use participants of the study to build a trusting relationship and the investigator had also used nurse coordinator/

and engage a senior oncologist in facilitation and the research assistant, as well as with an independent peer with special interest in health professionals' communication skills. Member checking was conducted during interviews and subsequently at the end of the analysis procedure. Informal checks of the findings with three participants from each professional category were done. A detailed audit trail that included a clear documentation of all the research steps and procedures was also created. To ensure credibility, all interviews were done in the place where the respondents feel comfort and security. A thorough presentation of the research context and findings is planned to enable an evaluation of the study's transferability.

#### Patient and public involvement

No patients were involved in this study. All 11 participants were oncology health practitioners, and no identifiable patient information were disclosed in their interviews.

#### **RESULTS**

Among all 11 participants, 36% were females. The work experience of participants specific to oncology centre ranges from 2 to 13 years, with an average of 7.5 years. ≥ The findings were presented as follows under two themes: typical experience which was categorised into two dimensions as typical experiences on outcome of BBN disclosure and typical experience on ethical issues. The second theme presents challenges related to breaking bad news (BBN), which are also categorized into four dimensions resource and organisational setup related, patient/family related, professionals related and sociocultural and religious related challenges. A summary of the solutions and strategies proposed by participants to enhance the current practice of BBN at the centre and across the country was also included. To showcase individual responses, the report included direct quotations from interviewed professionals, accompanied by their specialty and a unique code to identify them.

#### **Typical experiences**

#### Typical experience on outcome of BBN disclosure

The participants were asked to share their real experiences of any subsequential BBN outcome on the patient. They reflected positive outcomes of BBN on the patients' lifestyle, adherence, treatment outcome, relative

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psychological stability and great readiness to continue with further alternatives.

... There was an engineer with thyroid Ca to whom the treating surgeon told the possibility of some degree of mortality during and after surgery. Because of sudden onset and unexpected treatment option, he felt that he was going to die .... Then, I have informed him the available treatment options and outcomes, he became very glad and had ablation. And we became very good friends. On the contrary, another well-educated patient underwent ovarian cancer surgery and commenced a cycle of chemotherapy without being informed of her cancer diagnosis. She just discontinued the treatment due to the side effects. I tried to explain the severity of the illness and the values of the chemotherapy. In addition, I communicate her the chemotherapy side effects and control mechanisms. She was convinced and tolerated the chemotherapy and currently alive. (P11, a senior oncologist)

Participants noted that it is common for patients to immediately disappear post-BBN, regardless of how appropriately it was delivered. However, a senior oncologist contended that professionals ought to encourage patients to take adequate time to make decisions following it.

In my experience, patients to whom bad news was disclosed adhered with the treatment. Though there were some patients [that] disappeared immediately, they returned after some days with great readiness and acceptance of their condition. Patients were frustrated if bad news was broken after they had already begun the treatment without being aware of their diagnosis: for example, patients referred without being told/inappropriately told, and it was very hard to reassure them and change their perception. (P7, a senior oncologist)

According to P7, it is crucial to let patients begin treatment with enthusiasm rather than pressuring them for prompt commencement. This approach positively affects their adherence to treatment and follow-up.

I consider breaking bad news as "orce": assertion of one's death to his beloved one. For some days he will react and be in sorrow. Then after, some days he will think about his future life. Similarly, we should break bad news expecting some reactions and emotions for few days. The issue is to make them return when they are convinced. (P7, a senior oncologist)

#### Typical experience on ethical issues

Participants reported no formal ethical cases or issues arising from patients or families regarding inappropriate delivery of bad news (BBN). However, informal complaints were noted, where patients informally reported instances

of physicians disclosing truth in an inappropriate, inhumane, and harsh manner. A nurse shared her real experience as follows:

I have witnessed it twice. On one occasion, the patient's attendants, even a son, nearly physically assaulted the physician after he bluntly told the patient, "You will not live much longer." The physician, a senior general practitioner, and reassurance was necessary to them in this case... (P8, an oncology nurse)

Other ethical issue participants experienced was a dilemma among patients right to know the truth and family interference. Participants emphasised that family interference was the major factor for the truth to be hidden from the patient. Family either entered in the room prior to the patient or communicated using body language and alerted participants to hide the bad news from the patient. In such cases, participants reported that the priority should be given to the patient. The most common statement regarding this issue was they disclosed to the patient even though they might need to communicate the family for confirmation. Which is to make the relationship smooth and transparent, but it was not must.

Yes, it is common, the patient insists to know the status while the family interfere. But I am in the favor of the patient. At least I discuss to the patient the possibility. And I never allow the family to enter if the patient is not willing during breaking bad news. The family requests us not to tell the patient and reassure us as they could take care of him in the treatment process. But the patient should begin the treatment being aware of his status. (P11, a senior oncologist)

#### Major challenges

The participants were also interviewed about common situations which made the delivery of bad news challenging.

#### Resource and organisational setup related

According to the participants, the current organisational setup was the major challenge impeding the implementation of at least primarily principles embedded in SPIKES protocol or other international protocols as there was no contextualised standard protocols/guideline.

The major challenge is the setup. Now a days trained manpower (physicians, oncology nurses) is increasing in number. However, unless you sit together with the patient giving adequate time and maintaining your eye-to-eye contact in calm environment, it will be unhelpful and valueless. (P7, P11, senior oncologists)

Regarding the setup, the absence of calm environment and lack of a private room were the major challenges that made the process and outcome of BBN undesirable. The environment in the centre in general was not supportive to patients and families in addressing their needs.

Patients often travel from distant locations to receive treatment, as they can't access care near their homes.

Many arrive alone and are economically disadvantaged. Once at the center, they find no support—they need food, medicine, and somewhere to stay, but everything is quite costly here. This makes it challenging to provide palliative care. Consequently, patients often lose their mental stability, becoming depressed and anxious. In this situation, it is difficult to disclose bad news. (P5. a senior resident)

Lack of treatment access, long waiting list, fewer treatment alternatives and inadequate number of cancer centres were additionally reported as major resource/ organisational related challenges which complicated post-BBN management. As a result, professionals have been frustrated when they faced such cases.

A participant believed that they are overwhelming the patients with additional bad news which is frustrating both for the patient and the participants:

Patients need hope, further Rx options, and compassion. However, we do not have psychologists here to help them. Waiting for long (months to years) to get chemo and radiation therapies frustrates them further. It is double burdened bad news. Even it is frustrating to me after disclosing the diagnosis in calm. (P4, a year four resident)

The two senior oncologists had also emphasised this issue empathetically as follows:

The other heart-breaking challenge is that despite patients accept the diagnosis and decided to begin the treatment, they could not get it easily and immediately. It is disastrous. There is a situation you cannot help them while they accepted everything. So, what is the importance of breaking bad news unless we do not provide the treatment options, we informed them? (P7, P11, senior oncologists)

Participants repeatedly underlined the absence of any contextually standardised protocols or guidelines for the standardisation of the practice which might benefit both the patients and professionals.

In the absence of a formal uniform structure, the process relies on individual exposure and knowledge. In this context, oncology residents, particularly those in their third and fourth years, might deliver bad news once all investigation results are in, and oncology nurses may also be tasked with this responsibility. (P6, a fourth-year resident)

#### **Professionals related**

The major challenge reported by the respondents was lack of knowledge, poor perception and skill in BBN as many of professionals are not trained with bad news delivery. Inadequacy of time due to high patient flow, referral system, untruthful assurance and curriculum gap were also additional challenges underlined by the participants.

A senior oncologist emphasised poor knowledge and perception of some professionals regrading palliative medicine and BBN as a major professional related challenge since they might not give priority in day-to-day patient management.

There are health professionals with poor knowledge and perception about palliative care. They considered there is no importance of palliative care and breaking bad news for cancer patient. There are couple of professionals, because of poor understanding about palliative and hospice care, against referring the patient. (P11, a senior oncologist)

All respondents except one reported no formal BBN specific training received. However, some participants participated in informal, short-term palliative care training, the content of BBN was shallow and theoretically oriented. Thus, they even did not consider themselves as trained.

Most of the professionals working here did not take training on this topic. is practically oriented training modality through role play and on job training for all health professionals at oncology/other NCDs units is critical. it should also be included in courses of undergraduate program-like medical ethics. (P7 and P11, senior oncologists)

As a result of lack of specific professional capacity building related to BBN, they reported for little knowledge, poor perception, and skill on the delivery of and its consequence management.

The participants also claimed the content of BBN was incompetently included in undergraduate and postgraduate curricula. It was not sufficient to equip professionals with appropriate and effective delivery of BBN, practically. A senior oncologist agreed with this idea,

There is a deficit of both the undergraduate and post graduate curriculum regarding BBN since it only had palliative medicine content which focus on symptoms control. Late alone the GPs, the oncology residents do not know in detail except what they are exposed while we assist them in practical situation. (P11, a senior oncologist)

In contrast, a general nurse highlighted the importance of a naturally gifted communication skills and psychologically treating personality than having better knowledge and experience about the disease condition.

... Naturally gifted personalities are more valuable to deal with such issues. May be, better Knowledge make disease management effective. Experience might sometimes expose to situational adaptation. A 5-month experienced professional may break bad news better than a senior if one had naturally gifted soft skills. (P2, a general nurse)

Even though there is a relative increment in number of residents, seniors and oncology nurses, High patient flow vet limits professionals-patient discussion time to and the effectiveness of their communication.

... There is no counselling service, the DX and Stages may not be appropriately disclosed due to limitation of space, patient overload, and lack of standard setup. What we need is adequate time. (P6, a year four resident, P7, a senior oncologist)

Participants also recognised uninformed patients' referral as a challenge: patients referred either miss informed or uninformed about their DX as well as treatment alternatives and organisational setup of the centre. Consequently, BBN in this centre became very difficult to convince the patient as their expectation is different. At the end, the patients face reality shock and further frustrations, made the BBN challenging.

Referral system: they diagnosed and inform as there are alternatives and better treatment options beyond the capacity of the center and when they come here, long waiting list and unorganized setup. (P6, a year four resident)

Regarding the diagnosis misinformation or false assurance, the senior oncologists highlighted to what extent could it be challenging. 'In our setup, the patients come referred. So, Professional from other unit, prescribed the diagnostic tests and look the results but do not aware the patients about the real condition and the patients miss conceived the case and resisted us when we disclose the reality' (P7, senior oncologist). According to him it was challenging to convince the patient to change their prior perception which was wrongly assured by the previous physician.

#### Patients/family related

Low awareness and understanding level made the delivery challenging as patients would not be able to understand the implications of their diagnosis. The other challenge was low probability to meet the patient again since there is poor acceptance level of bad news at initial time. Participants might not find them on the next day either due to their personal preference or long list of treatment services.

Another challenge is low patient's acceptance on first day in breaking bad news, so you should have a second chance to meet the patient to inform the details, blandly, you sometimes might find patients with low level of consciousness to the disease. They may consider it as infections, especially mothers from rural areas. How could you deliver it in the way they could understood and contextualizing with their sociocultural context is the other challenge? How do you convince them to give it attention? (P7, P11, senior oncologists)

Family interference of the delivery process was the other common challenge underlined by participants to effectively implement BBN. Commonly, family refused

bad news disclosure to the patient. Participants also reported that sometimes families will be uncertain how they would care for the patient. Because they would be hopeless considering the shocking news and unfavourable setups.

Both Patients and family's awareness towards disease condition is low, as a result, they will be emotional when bad news is disclosed. During disclosure some family may be hopeless, disturbed and leave the patient alone. It may lead the patients to depression and anxiety. (P5, a senior resident)

Patients and family poor awareness and wrong perception on chemo and radiation therapy, and long waiting lists of treatment services were also additional factors that affected the delivery process adversely. These factors had high impact on patients to be in frustration when the bad news was disclosed.

... it is disastrous. How could you communicate the patient privately? There is noise and chaos outside due to high number of patients waiting for you at the corridor. On the other hand, there are families who are requesting the patient not to be told about his [or] her current disease status. In addition, there are some patients have wrong perception of chemo and radiation therapy considering them as lethal. When you break bad news and tell the treatment options, they start to frustrate. Economically poor families are commonly refusing the treatment options and use holly water or other traditional means. (P11, a senior oncologist)

Many respondents mentioned the most frustrating spect of delivering bad news was the waiting list to get aspect of delivering bad news was the waiting list to get treatment. They reported that treatment services are incomparable with the patient load and no wider alternatives. 'Another factor is our waiting list: after you informed training, and simi the patient about the cancer disease and its treatment options then you may appoint them 4, 6 months, even 1 year later for radiation. So, the patients look for another traditional alternative' (P7, P11, senior oncologists).

#### Sociocultural and religious challenges

Participants raised family's wrong assumption of undesirable impact of BBN on the patient's life. Family believed that the patient will be fragile, which is in contrary to beliefs held in Western culture.

Economic status did not differently affect BBN. Those economically strong family would have refused BBN to the patient; however, they were committed to discuss about further treatment alternatives. Religiously supported patients found to be strong during the process as they may admit death as common life event. According to the participants, religious institution had great influence on acceptance of BBN and adherence on the modern medical managements. Participants advocated the effort of some religious institutions on mutual use of modern medicines and ritual alternatives.

It is relatively good in case of some religions since they may use religious alternatives when the waiting list is long whereas specific to one religion followers (the participant stated the religion), they asked us to write a case summary and return after having pray in the religious place institution. There is no encouragement to use the modern medicine with the religious alternatives in combination. Rather, sometime later after withdrawing the treatment, they will return to confirm whether the disease is cured or not. This issue needs great movement and effort. (P11, a senior oncologist)

## Participants suggested solutions and strategies

Overall, participants emphasised the need for improvements in the current practice of BBN at organisational level to ensure appropriate delivery and better patients' outcome. To improve the appropriateness of the delivery and effectiveness of BBN, participants suggested adequate number of trained professionals, initiating psychotherapy service, developing guidelines/protocols, and rearranging private rooms, and advocating supportive and palliative services to patients and families.

Breaking bad news training should be delivered separately for all undergraduate/graduate program trainees before their graduation. The other thing the government and hospitals should give special attention on organizing the setup and assigning the physicians. Every physician should be aware of how to break bad news and give attention to it. (P11, a senior oncologist)

Regarding the type of training, participants emphasised short-term, continuous, practically oriented on job trainings. '... The training is better to be delivered practically through role model or on job training for all health professionals at oncology/other NCDs units' (P7 and P11, senior oncologists). In addition to this, participants also stressed post-BBN management to be included in the training 'the training should be given focusing on the ways of handling post BBN consequences' (P2, P5, a general nurse and a senior resident). Besides, including BBN in the curriculum was also suggested. '... And BBN should also be included in courses of undergraduate programlike medical ethics' (P7 and P11, senior oncologists).

In addition to this point, a resident stressed the important of considering post-BBN supports to the patient and families.

There is difficulty in addressing supportive and palliative services. So, without availing those things, it is difficult to disclose bad news. It may lead the patients to depression and anxiety. So, team of psychiatrists, and religious persons is necessary to manage those things while breaking bad news. Families are not aware of the nature of the disease. During disclosure they may be hopeless, disturbed and leave the patient alone. (P5, a senior resident)

Professionals' commitment in updating their knowledge was also cited and participants suggested an alternative approach of training specialised counsellors if training all responsible professionals is challenging.

A separate unit to deliver breaking bad news with a specially trained clinical counsellor may be a solution if the physician-patient ratio is high. Professionals should give attention to it as their day-to-day duty as some patients attempt suicide. I believe that what we need is adequate time. (P7, a senior oncologist)

At a country level, bearing in mind the comparative increased attention of FMOH and other stakeholders on NCDs, participants had also advocated an attention for palliative medicine and BBN. The other effort emphasised was community awareness enhancement, at large. Using media to promote information related to cancer, early screening, follow-up of treatment and stigma was suggested, as participants experienced patients who wrongly perceived cancer as a communicable disease, resulting in their stigmatisation.

Expanding cancer centres and increasing oncologists in number, as it has been initiated recently, were identified as an important strategy to reduce the patient load to the centre. This in turn, provides participants adequate time and environment to break bad news, effectively. Most of the participants argued the government/FMOH to execute its responsibility. A physician stated:

The ministry of health should take the responsibility considering it as one of the major issues. Sometimes patients are referred from the health center only for further explanation. It is unnecessary expenditure of resources; we should reduce unnecessary ups and downs: If we disclose everything here and have communications with health centers to follow them for palliative care. Therefore, the MOH should give attention on palliative medicine and breaking bad news. (P11, a senior oncologist)

The other major issue recognised as suggestion was collaborative works with religious institution in encouraging patients to use modern medicine with ritual heals. Participants reported that some religious leaders teach patients that cancer could not be managed by modern medicine associating the cause with devils.

## Conceptual model to explain challenges of BBN practice in BLSH, oncology centre

Based on the findings of the study, generally it is challenging for health professionals to break bad news to patients with cancer at BLSH, oncology centre. The following model was developed to illustrate the impact of various dimensioned challenges identified by health professionals on their BBN practice (figure 1).

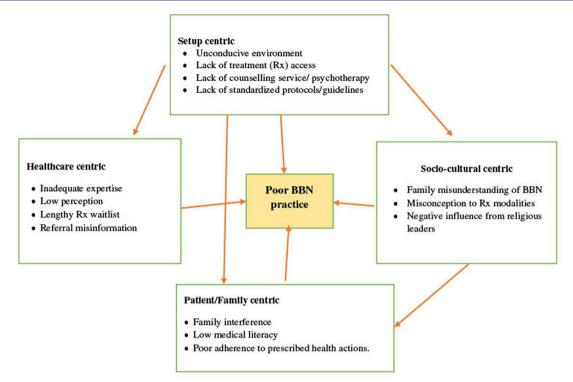


Figure 1 Conceptual model illustrates how breaking bad news practice related to the challenges of oncology health professionals, March 2019, Black Lion Specialized Hospital, oncology centre, Ethiopia. BBN, breaking bad news.

#### **DISCUSSION**

The findings of this study are examined in the context of common experiences with BBN outcomes and related ethical considerations. Additionally, the discussion addresses the various levels of challenges that were reported to affect the delivery of bad news from different angles.

#### Typical experience on outcome of BBN and ethical issue

All participants in this study reported positive outcomes of BBN to patients. However, they experienced post-BBN immediate disappearance of patients regardless of the appropriateness of the delivery. Similarly, another study acknowledged the impact of the disclosure manner on the therapeutic course. Negative consequences of inappropriate delivery were identified as loss of trust, disappointment, lack of cooperation, therapeutic non-compliance and passive participation on behalf of the patient.<sup>2</sup> Disclosing the truth is a crucial aspect of conveying bad news, as it is necessary for informed decision-making.

Regarding real experience on ethical issues, participants reported informal patient/family instigated ethical issues on professionals' inappropriate disclosure. Patient right to know the truth versus family interference were identified as a major ethical issue, which is corresponding to studies done in Omani<sup>11</sup> and Greece.<sup>2</sup> It underscores the challenges in communication related preference within oncology care in Ethiopia, particularly when conveying bad news.<sup>20</sup> Participants of the current study reported a priority given to the patients in this situation. In contrary to this, a study described usual disclosure of bad news to the family rather than the patient himself or herself.<sup>2</sup>

Decisions to tell the patient were almost always based on the family's preference, driven by concerns that patients might not handle bad news well and fear of conflict with the family.<sup>21</sup>

It is crucial to deliver bad news sensitively and allow patients sufficient time to consider their options. Hence, participants emphasised the need to improve current approach to BBN to proper delivery and improved patient outcome. Tailored training and guidelines that consider cultural nuances are essential for both healthcare professionals and the public. 11 21

#### Multiple-level major challenges of bad news disclosure

According to the participants of this study resource/ organisational, professional, significant patient/family, and sociocultural and religion related challenges of the delivery of bad news, as in several international studies<sup>2–5</sup> 10 <sup>22–24</sup> are discussed as follows.

Resource/organisational setup dimension

Participants underlined unconducive environment was the major organisational related challenge to achieve the major organisation the

patients' need, which is similar to other studies.<sup>2</sup> 11 25 26 In addition to this, long waiting list due to lack of treatment access and inadequate number of cancer treatment centres, and fewer alternative treatments are challenges affecting post-BBN patent condition. As a result, both patient and care providers have been frustrated and hopeless.<sup>25</sup>

Participants in this study also stressed the lack of contextually standardised protocols and guidelines for BBN made the delivery process challenging, which is

inconsistent and informal. In line with a study conducted in Greece, current practice concerning bad news disclosure was based on personal experience rather than on recommended or standardised procedures.<sup>2</sup> Another study also reported participants individualised communication style to meet the needs of their patients as they were unclear about best practices.<sup>27</sup>

Clinicians' perspectives on BBN model and crosscultural factors shape their practice.<sup>28</sup> Several existing protocols and guidelines for the effective delivery of bad news can be incorporated in communication skills training. The standardised approach of a specific protocol such as SPIKES and BREAKS' can be a helpful guide for the clinician, or it can provide a basis for the development of adequate communication.<sup>2 3</sup> Currently, up to the researchers' knowledge, there is no evidence supporting superiority of one protocol of BBN over another. However, specialised training in the use of such guidelines can provide support to health professionals' practice. A contextually standardised protocol and guideline is needed to make the practice uniform. Besides, a study stressed continuous doctor-patient relationship, leadership, supportive informational material, such as leaflets.2

To improve the appropriateness of the delivery and effectiveness of BBN participants suggested adequate number of trained professionals, developing guidelines/ protocols, conducive environment, initiating psychotherapy service, advocating supportive and palliative services to patients and families.

## **Professional dimension**

At a professional level, on top of lack of knowledge, poor perception and skills, and being untrained, participants clearly indicated the influence of inadequate time due to patient overload in their ability to successfully deliver bad news. Similarly, other studies reported a major lack of knowledge and skills regarding the optimal ways of BBN and overall communication with patients in clinical settings. 12 They also pointed out that due to work overload, communication issues were not set as priorities and often fatigue led to mismanagement of disclosure.<sup>2 23 29</sup>

Regarding training, consistent to the current study, none of the participants received relevant formal training in communicating the bad news.<sup>2</sup> 11 30 As participants revealed, the attention and coverage of BBN both in undergraduate and postgraduate programmes is very little and not practically oriented. Even few participants who are trained with palliative care clearly stated that they consider themselves untrained with BBN as the content was insufficient and inconsistent. It might be attributed to lack of adequate formally structured education on topics such as health communication, medical ethics and clinical/health psychology. Substantial knowledge available on Western people's perspectives on BBN, however, little attention has been paid to Africans' perspectives. <sup>712</sup> Other studies also noted continuous medical education training in communication skills has been found effective

in improving patient centred attitudes of health professionals.<sup>2</sup> <sup>22</sup> <sup>31</sup> Still, as the senior oncologist revealed, the content of BBN was not included in the curriculum of oncology residents while they have been taking palliative medicine courses. Currently oncology staff are making efforts to incorporate these topics in the trainee curriculum, with a focus on the enhancement of students' interpersonal skills on patient centred approach. Therefore, there is a need to train professionals in clinical and communicative skills equipped them in appropriate and

effective bad news delivery. Lack of formal training courses for clinicians on the important communication task of bad news delivery can impede success.<sup>2</sup> <sup>32</sup> <sup>33</sup> Well-designed interpersonal communication training programmes and guidelines are expected to be implemented at academic and clinical level to enhance the quality of care. 34 35

Regarding the type of training, participants emphasised short term, continuous, practically oriented on job trainings reinforced with post-BBN management. Expanding cancer centres and number of oncologists were identified as an important strategy to reduce the patient load to the centre. training some independent counsellors to whom BBN cases would be referred was stressed as an alternative suggestion.

#### Patient/family dimension

Regarding patient/families related factors: participants acknowledged family interference, low awareness and understanding level of both patients and families, congruent to studies done in Omani and Greece.<sup>2</sup> 11 Patient's age, health status and educational level were mentioned as three factors influencing the way bad news were conveyed.<sup>2</sup> Being elder obliges professionals to **3** disclose to families. A study done in Turkey showed that the only significant factor 'do not tell' requests from relatives, which is also reported in Western societies. 3-5 10 The other concern is lack of opportunity to meet the patient again since they will not return due to low acceptance. In the same way, the contribution of continuous doctor-patient relationship to manage difficult situations, including the delivery of bad news was highlighted.<sup>2</sup> Doctors reported that disclosure was impeded by attitudes such as distrust and discredit they often encountered with patients and relatives.<sup>2</sup> To overcome the above-mentioned challenges, participants of this study underlined an attention for participants of this study underlined an attention for palliative medicine and BBN. They suggested for massive community awareness, using mass media to promote all information related to cancer.

## Sociocultural and religious dimension

Along with sociocultural influence, participants raised families' wrong assumption of undesirable impact of BBN on the patient's life: if bad news is disclosed to the patient, they will be fragile, which is in contrary to Western culture. 12 36 Similarly, relatives' preference or resistant cultural behaviour to open the topic discussion with the patient is a major cultural problem, so communication with a patient's family emerged as a major determinant of physicians' practice. <sup>2</sup> <sup>11</sup> This suggests that health professionals should consider cultural differences and adapt their approach to delivering bad news based on individual preference. <sup>36</sup> Respecting patient autonomy requires understanding its complexity and adjusting healthcare practices to fit both personal and cultural preferences. <sup>37</sup>

Despite some religious leaders who encouraged patients to avoid modern medicine, it. religiousness and theologian supported patients found to be strong during bad news breaking.

This study reported the complexity that exists around relatives' roles in the communication processes and the overall care of the patient Some physicians prefer disclosing news to a family caregiver rather than the patient. The function of the family seems to play a crucial role in addressing health issues. Specifically, life-threatening diseases impact on the entire family system, prompting it to respond to the problem collectively. The family acts as a decision-making unit and the concept of individual autonomy turns into family autonomous. Unlike other societies, in Western cultures, there is a predominant belief that patients should have full disclosure of bad news if this is their wish.

Overall, these aspects of the current sociocultural background should be considered in any attempt to improve the existing bad news delivery, and health professionals need to acquire the appropriate skills to balance between contradicting features and the patients' and families' actual information, preferences, and needs. <sup>24</sup> Hence, the strategies for BBN vary across different cultures and nations. <sup>1</sup> Moreover, collaborative works with religious institution is important in encouraging patients to use modern medicine with ritual heals.

Generally, current practice is not standardised with any framework or protocols and delivered by untrained professionals on BBN. There are many challenges of the process and effectiveness of BBN. Hence, there is a critical need to improve the practice. Change efforts towards empirical BBN practice may focus on development of contextualised, content and context specific practical oriented training programmes and curriculum interventions. Yet, it is important to consider factors such as health professionals—patient ratio, perception, sociocultural and religious related characteristics, and lack organisational setups for conveying bad news.

#### Strength and limitation of this study

The study is the first qualitative study addressing experience and challenges related to BBN during any health-care provision, beyond diagnosis time. Adequate number of sample size with purposeful—maximum variation—sampling techniques was implemented to reduce bias, include diverse views and collect quality information. However, further studies should consider some limitations of this study, first the findings present only the health professionals' perspectives of the process of BBN. So, some pertinent findings of patients and families may

be missed. Besides, practice related findings relied on self-report.

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Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and ethical clearance (Prv/061/11, date: 15 March 2019) was obtained from ethics committee of Department of Preventive Medicine, School of Public Health, College of Health Sciences of AAU and presented to the oncology centre head. Confidentiality was assured using a code instead of the participant's name and the audio files were password protected. Participants gave informed consent to participate in the study before taking part.

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