

APPENDICES

Appendix 1. Consent form

INFORMED CONSENT FORM

Dear Volunteer,

Thank you for your interest in this study, which is examining the experiences of physicians communicating poor prognosis to patients and their families. The study is being conducted by Alexandra Caulfield, a Master's Student in Global Health at Karolinska Institutet, in Stockholm, Sweden, and a medical doctor by training. I kindly ask your permission to recruit you into this study, which I will proceed to describe. To ensure that you are informed about the study, please read the following information and ask me to explain anything which is unclear. You will receive a copy of this form to keep.

Why have I been asked to participate?

Your experience is the focus of this study. Specifically, I am interested in the views of physicians in Cape Coast Teaching Hospital, who have experience communicating poor prognosis to patients and/or their families on a weekly to monthly basis. This research will be submitted as a Master's Thesis at Karolinska Institutet in Sweden.

What does participation involve?

I would like to interview you about your experiences and request that you complete a short questionnaire relating to your background. Interviews may last up to 1 hour.

What are the benefits?

Your participation helps us to understand the views of physicians working with patients who are facing serious illness and possible end of life care. Such information is important to identify challenges in providing such care, and to inform development, support and training for staff.

What are the risks?

We do not foresee any risks or discomfort to you during the interview.

Will my information be kept confidential?

Yes, all information collected in this study will be treated with strict confidentiality. Interviews will be anonymised on tape and in written format. The final written thesis will include quotations from participants arranged in themes. For this, and if the results of this study are additionally reported in a medical journal, identities will be kept anonymous.

Will I receive any compensation?

You will not receive any compensation for this study.

Am I free to leave the study?

Your participation is entirely voluntary and will have no adverse consequences for you should you choose not to participate or choose to leave the research at any point. You may choose

not to answer a question if you wish. Any such decision will be respected without any further discussion. If you wish, you will have the opportunity to discuss your feelings with the interviewer.

Who can I contact for further information?

If you have any questions concerning this study, please do not hesitate to contact Alexandra Caulfield on phone number +447769574743 and alexandra.caulfield@stud.ki.se. If you are unable to call a foreign number, please contact Dr. Yvonne Nartey (the Cape Coast project lead) on +233246794065. This research has been reviewed and approved by the Cape Coast Teaching Hospital Ethical Review Board. If you have any questions about your rights as a research participant you may also contact the Cape Coast Teaching Hospital Ethical Review Board via landline on 03321-34016 or email address info@ccthghana.org.

Statement of participant:

I have read the above information, or it has been read to me. I have had the opportunity to ask questions about it and any questions have been answered to my satisfaction. I consent to participation in this study voluntarily.

Date

Name

Signature

Statement of researcher:

I confirm that I have explained the above information fully to the participant, including information about risks and benefits, so that they are able to make an informed decision. I confirm that the participant was given an opportunity to ask questions and that I answered any questions correctly and to the best of my ability, and that consent has been given voluntarily.

Date

Name

Signature

Appendix 2. Interview guide

Note: Questions which are highlighted in bold are those prioritized if time was running short.

Introduction

Thank you for agreeing to take part. I really appreciate your time.

First, I'd like to ask a little bit about your experiences discussing prognosis with patients who are unlikely to recover from their illness, and then discuss how you cope with this. I realise that experiences vary from person to person, so I want to emphasize that there are no right or wrong answers. I just want to understand experience. To be clear, this is a research study, and is not linked to hospital management. Your answers are confidential; only my small group of research supervisors will have access to the data before it is summarized. If any of my questions aren't clear, please let me know, and if you would like the interview to stop at any point, then please let me know straight away.

- I understand from my colleague Dr. Yvonne Nartey that you're a XXXX in the Internal Medicine Department. Is this correct?
- Can you tell me a bit more about your professional background?
 - Prompt: medical school, time working, time at CCTH

Thank you. I'd like to now ask about your experiences communicating prognosis to patients who are unlikely to recover from their illness.

THEME 1: Context

- **I am interested in understanding how you talk with patients when they cannot survive a disease. A term sometimes used is 'poor prognosis' - do you use this term?**
 - If yes, what comes to mind?
 - If no, what terms do you use or how do you discuss this with patients?
- **Could you give me an example of when you did this?**
 - If they describe a positive experience: could you describe a time when the conversation went less well? What were the reasons for this?
- **How often do you give this information to patients?**
- **Where do these conversations take place?**
 - Prompts: For inpatients? For outpatients? Who chooses the location?
- **How long do these conversations take?**
 - Probe: what does this depend on?
- **Who is present for the conversation?**
 - Prompt: E.g. family, seniors, juniors, anyone else?
- **What role do the family play in these conversations?**
 - Probe: what are the advantages of this? And the disadvantages?
- **What role does religion play in these conversations?**
 - Probe: how would you describe the relationship between medicine religion or alternative remedies in this conversation?

I'd now like to find out a little bit more about the patients you are talking to....

- **What kind of conditions/diagnoses do the patients have?**
 - Probe: How does this affect the conversation?
- At what stage in their illness would you have this discussion?
 - Who decides when to have this discussion the patient or family?
- How do patients respond to this?

- Outside medical information, what kind of information do you have about their background?
 - Prompt: E.g. social situation, family support?
 - Probe: How does this affect the conversation?
- Would you see the patient or family again after this conversation?

And now thinking about the content of the conversation...

- What kind of topics do you bring up?
 - Prompt: E.g. quality of life, prognosis/life expectancy, spirituality?
- Which of these topics do you focus on?
 - Probe: What influences this focus?
- **Does what you want to talk about differ from what the patient wants to talk about?**
 - If yes, in what way?
 - Probe: How do you negotiate this?
- **Do you discuss death and dying in these conversations?**
 - Probe: if yes, how do you discuss that topic?

THEME 2: Perceptions and Roles

- **Tell me how you feel during these conversations?**
 - Probe: what makes you feel this way?
- Is this different from how you feel when talking to patients or families about other topics?
 - If yes, in what way?
- **How do you feel directly after the conversation?**
- **How do you feel about discussing the topic death and dying?**
- How much emotion do you think a physician should show when communicating poor prognosis to patients and their families?
 - Prompt: for example, how do you feel about crying with or in front of a patient or their family?

I'd like to focus now on the role of a physician in this conversation.

- **Doctors have many tasks and responsibilities. You are clearly a medical expert. In addition, how do you think about your other roles?**
 - Prompt: E.g. Counsellor, Advisor, Communicator, Collaborator, Manager, Health Advocate, Scholar, Professional
 - Probe: what do patients expect from you as a doctor?
- Is this different from the roles of a doctor in other conversations / settings?
 - If yes, in what ways?
- Are nurses involved in these conversations?
 - If no, would you change that?
- **When the hospital cannot treat a patient more what other option do patients have?**
 - Prompt: e.g. religious remedies, alternative treatments

THEME 3: Support and Training

I'd like now to move to the final part of the interview. In this section, I'd like to hear your thoughts on whether these conversations could be improved, both for you as a physician, and for patients and families.

- **Do you think communicating poor prognosis to patients could be improved in any way?**
 - **If yes, how?**
 - Prompts: For patients? For families? For physicians?

- Would you include any additional people in these conversations?
 - If yes, who would this be?
 - Probe: Would it be possible to organise this?
- **How much of a role do you think communication training plays?**
 - If little, what else do you think prepares you?
 - Prompts: E.g. medical school, personal experiences, professional experience
- **If you could design a training programme for communication of poor prognosis, what would you include?**
- **How have you felt about discussing these experiences today?**
- **Would it be useful to talk with colleagues about these experiences?**
 - If yes, what form would that take? E.g. coffee break, more formal set-up

CONCLUSION

- Thank you very much for your time. I have learnt a lot.
- Is there anything we have not discussed which you would like to mention?
- Do you have any questions for me, or anything you would like me to explain further? If you think about anything later on, feel free to get in touch with me.
- I will be in Cape Coast for a month. Would it be possible for me to get in touch with you if I am transcribing the interview and I find that something is not clear?

Appendix 3. Demographic questionnaire

Demographic Information

Participant ID:

Age:

Gender:

Job *eg. House Officer, Senior House Officer, Specialist etc:*

Where did you train at Medical School?

How many years have you been working since Medical School?

How long have you worked at Cape Coast Teaching Hospital?

What training have you received in communication skills?

And in communicating poor prognosis or 'breaking bad news'?