Note: This is Online Appendix 1 of Kwaitana DP, Van Breevoort D, Mnenula MC, Nkhoma K, Harding R, Bates MJ. Family caregiving challenges in primary palliative care for older people with multimorbidity in Malawi – A cross-sectional qualitative study. Afr J Prm Health Care Fam Med. 2026;18(1), a5490. https://doi.org/10.4102/phcfm.v18i1.5490

TOPIC GUIDE FOR OBJECTIVE II: IN-DEPTH INTERVIEWS FOR CAREGIVERS

Opening statement

Thank you for agreeing to take part in this research interview. My name is _____ and I am a member of the team working on this study. Today we will have a conversation about your family member's/friend's illness, how it affects you, about your experiences of their care, and how you would prefer care to be provided. I am interested in hearing your thoughts so please do feel free to openly tell me what you think. The interview should take about 40 minutes. I will record our interview, but I will not start recording until we are ready to talk and I will tell you when I am switching it on.

We may cover some sensitive topics during the interview. You can pause or stop the interview at any point or skip any questions should you wish to. If anything I ask isn't clear, or you would like time to think about your answer, or you would like to raise something that you think is important, then please do tell me. I would like this to be a conversation so that I can find out what you think and what matters to you as someone caring for a family member/friend with lung illness.

What we talk about will not be shared directly and I will take out any names or places so that when I describe what family members/friends have told me, they will not be able to know who I have interviewed. Also I will not share anything directly about you with your care team. However, if I am worried about your safety or anyone else's safety then I will let your care team know and I will let you know that I am doing that.

Could I please just confirm that you have signed consent form and read the information sheet? And are you happy for the interview to be audio recorded today? Do you have any questions before we start?

Ok, I am turning on the recorder –

START RECORDING

SECTION 1 - INTRODUCTION

- Could you tell me a bit about yourself?
- Please tell me a little bit about when your relative first became unwell?
- Please could you tell me about your current experience of having an elderly relative with multimorbid serious illness? On a day-to-day basis, what are your relative's main needs, priorities and concerns?

a) How does serious illness affect your relative on a day to day basis? (probe: physical needs (breathlessness, fatigue, sleep)
b) How does it affect their psychological needs? How does it affect how they feel? How are they able to cope?
c) How does the illness of your relative affect you? (probe for a and b above)
d) What have been the effects on both your lives socially?
e) How has the illness affected your relatives religious or spiritual needs, how has it affected you spiritually?
f) What would you say are your main priorities at the moment? Are there certain aspects of your or your relative/friend's health that are most important to you at the moment?

g) Is anything in particular causing you concern or distress? What would you say are the things you'd most like to be managed? (e.g. symptoms, unmet needs) (probe (g) for the patient)
h) How do you think their illness will affect you both in the future? Do you have any particular concerns or worries about the future?

SECTION 2

[Referring back to any specific points raised above] - In what ways are [these needs] being met by the health services? In what ways are they not being met?

a) When you and your relative visit the health facility, in what ways are your problems and concerns assessed or discussed with the doctor? (probe across these domains: physical/psychological/ social/religious/spiritual)
b) Do you feel health professionals know what matters and what is important to your relative? What are the things your relative values in life? (probe personal values, moral values) Do you feel the care you are given focuses on what is important to your relative? Do you feel the care you receive addresses the things that matter to your relative?
c) Could you tell me about whether the people managing your relative's care listen to you and understand your needs and concerns and those of your relative?
d) Has your relative's care been tailored to their/your needs in any way, and if so, how?
e) What should health care professionals do to make sure they are providing care that meets your relative's needs?

SECTION 3

How would you describe the care that your relative has received for your condition?

How would you like care to be delivered to you? (What would 'good' care look like to you? How do you feel that your care could be made better?)

a) How do you feel about your relative physical caring environment when you go to the community health clinic/district hospital? How would you like the caring environment to be?
b) What kind of support did you and your relative receive? How did you feel about that support?
c) What could clinicians do to better understand needs and support for you both?
d) When you go to the community health clinic/district hospital, how is your relative treated as an individual? How do care staff behave towards you both?
e) How would you like them to behave towards you both?
f) At the community health clinic/district hospital, how have health professionals communicated and interacted with you and your relative? What have they asked you and your relative about? What problems do you think they expect your relative to talk about at appointments? Are there any problems that you think they would not expect your relative to talk about?
g) When there are any decisions or choices to be made about your relative's care, who was involved in that decision making? To what degree was your relative involved in those decisions? To what degree were you involved?

h) To what degree would you like your relative to be involved in those decisions? To what degree would you like to be involved in those decisions? How could health professionals help you to feel part of those decisions?
i) How would you describe the way in which your relative's care has been planned and coordinated? Could you tell me about how different appointments are scheduled? How do they decide when to go to the community health clinic/district hospital?
j) How would you like their care to be coordinated? E.g. How would you like appointments to be arranged?
k) Has anyone ever talked to you and your relative about how their care needs might change over time, and about your future wishes/priorities for care?
l) Would you want to have that discussion about their care in the future, and why? How would you like your and your friend/relative's future wishes and priorities for care to be discussed?
m) How in control do you and your relative/friend feel in managing their health? What do you both do yourself to manage their health problems? What works best for you at home?
n) How would you feel about them being more/less in control of managing their own health? How would you feel about you and your family being supported to care for themselves at home when possible? What would be good/bad about that and [If they respond positively] - How could we do that?
o) How are you involved in self-management of your illness? What is it that you are able to do at home by yourself or with the help of a family member? what could be done so that you should be in full control of your health?
p) What might help you to take care of yourself/self-manage your illness at home? (probe: what factors will facilitate self-management at home)
q) What are the barriers to self-management among the elderly people with serious illness? What factors will hinder you to manage your own illness?
r) How would you like your doctors and nurses to communicate with you and your family? What would you like them to ask about? What could be done to make sure that the people that deliver your care interact with you and your relative [in the ways that you want]?
s) How have you found the communication between the team of people managing your relative's? How have they worked together? How have they collaborated/coordinated? Have they kept each other, and you, informed?
t) How would you like them to work together?
u) What do you think about the way in which any information has been given to you and your relative about their disease and care? How has it been provided? Is it enough information? Have you had the opportunity to ask the questions that are most important to you? Why? Do you get the answers and information that you want?
v) What are the most important questions for you about your relative with multimorbid illness? What would you like to know about their disease and care? How would you like that information to be shared? Is there anything you would not want to know about their disease and care? Was the information given to you in a way that you could understand?

a) What services are provided to you at this facility when you come for medical attention with your relative? (probe: laboratory tests, radiology etc). How much do you pay for these services? (probe for each of the services mentioned)
b) Are there specific days or special clinic days for the elderly with multimorbid serious illness? Which are these days? How often do you visit the clinic? monthly, every three months? every

six months? Are these on appointment basis or visits made only when your relative is feeling unwell? What are the main issues/reasons that make you visit the facility?

c) What type of drugs is your relative taking? How often do they take these drugs? What are the costs of the drugs, what are the costs of diagnostic tests? How often are these diagnostic tests conducted? Who pays for these costs? How do you travel to access the services or to visit facility? (probe Ambulance, taxi, own transport? who pays for transport services)
d) Where else does your relative go to seek health care services for their illness other than at this facility? (probe: traditional care, counselling, complementary services), How much do these services cost?

a) What do you think might be the best possible way for health care professionals to give care to elderly patients with multimorbid serious illness when they visit the health facility?
b) What changes to how the care is delivered would make the biggest differences for your relative while attending the health facility? If health professionals could change one thing, what would you choose?

Closing statement

If there is anything you would like to add about your experiences of care or anything we have missed out/not spoken about, you can always contact us afterwards. I'd like to thank you for taking the time to be interviewed today, we really appreciate it and your views will be a great help to us.

(END RECORDING)