Author’s response to reviews

Title: A reflection of ethical and methodological challenges of using separate interviews with adolescent-older carer dyads in rural South Africa

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Version: 1 Date: 03 Apr 2019

Author’s response to reviews:

METH-D-18-00194

“Are you going to tell my grandmother that I am pregnant?”: Ethical and methodological challenges of research with adolescents and their older carers in rural South Africa Dumile Gumede, MSocSc; Nothando Ngwenya; Stella Namukwaya; Sarah Bernays; Janet Seeley BMC Medical Ethics

We thank the reviewers and editor for their constructive comments and the opportunity to resubmit this manuscript after revision.

In the tracked-changes version of the manuscript, we show additions in red.

In this document, our responses to the reviewers’ comments are summarized below each comment

Reviewer reports:
Jantina De Vries (Reviewer 1): Review of "Are you going to tell my grandmother that I am pregnant?: Ethical and methodological challenges of research with adolescents and their older carers in rural South Africa"

Major comments:

- One overall critique of the paper is that in many of the sections, you seem to have limited yourself to only presenting the particular manifestation of an ethical or methodological issue in your study, without also attempting to a) link your experiences to the broader methodological literature around dyad interviews, if there is such a literature and b) drawing some broader lessons learnt or recommendations for challenges in and opportunities for conducting this research in an LMIC.

Having read this manuscript, I now know about the particular issues you faced and how you addressed them, but I don't really feel like I have broader insight into the opportunities for dyad research in SA or in LMICs in general. Although you do some of this work in the Discussion, I think your manuscript could be enriched if you wove this critical narrative into your paper. I would really urge you to look at each of the issues you identified and try to situate those issues better in the broader (ethnographic and dyad-specific) literature. A good example is the final issue you raise, about interviewers preferring one side of the dyad more than another (e.g. in this case, feeling more comfortable with and sympathetic towards the older carers than the adolescents). Have others also identified this as a methodological issue in dyad research? Is this an issue that is more likely to arise in more strongly hierarchical societies? How does gender play into this? And, importantly, how would you resolve this issue in future? A second example is the issue of reciprocity obligations (see also comment lower). How has this issue described by other ethnographic authors? See for instance Nyambedha, E. O. Ethical dilemmas of social science research on AIDS and orphanhood in Western Kenya. Social Science & Medicine 67, 771-779, doi:DOI: 10.1016/j.socscimed.2008.02.024 (2008) where he works through some similar issues. Also Huisman, K. "Does This Mean You're Not Going to Come Visit Me Anymore?": An Inquiry into an Ethics of Reciprocity and Positionality in Feminist Ethnographic Research*. Sociological Inquiry 78, 372-396, doi:doi:10.1111/j.1475-682X.2008.00244.x (2008). I am sure there are many more.

RESPONSE: We thank the reviewer for suggested articles by ethnographic authors. We additionally now discuss ethnographic and dyadic literature in the Background section.
In line with that comment: Whilst the stated main aim of this paper is to offer a methodological and ethical critique of the use of dyad interviewing methods in an LMIC, this does not stand out very clearly in the title or in the abstract as currently phrased. E.g. the use of a quote in the title, whilst very appealing, suggests to me that this paper will present an analysis of interview data - and a similar suggestion is created in the abstract. I would strongly suggest that you rephrase the title and abstract somewhat to make it clear that a) this is a methodological and ethical critique of b) the use of dyad interviewing methods in c) an LMIC. I.e. I would suggest that you much more strongly position this as a methods paper (where the actual research you did is secondary to that objective).

RESPONSE: We thank the reviewer for highlighting this gap and the suggestion to position this as a methods paper. We have now rephrased the title and abstract to make it clear that this is a methodological and ethical critique of the use of the separate interviewing method with care dyads in an LMIC. The revised title is: ‘A reflection of ethical and methodological challenges of using separate interviews with adolescent-older carer dyads in rural South Africa’.

- Line 273: I wonder if you could add a sentence there to indicate whether you approached any adolescents (or even older carers) who subsequently refused? Did you only approach 6 dyads and did all those approached consent to participate (if so, that would suggest that your concern may be real). Also, maybe you probed this concern with the adolescent participants in the duration of the study and if you did, perhaps you could share here whether they thought this was a concern.

RESPONSE: There were no refusals or participants who withdrew during the study. We have now added a sentence: All the six dyads approached, consented to participate in the study.

- A related question is whether the carers were actually aware that their dependents were participating in the DREAMS programme? Were they likely to know the facilitators? How did the facilitators get their contact details?

RESPONSE: We have amended our explanation to clarify that the carers knew that their adolescent grandchildren participated in the programme. They also knew the facilitators as these facilitators were local people who were well-known in the community. Since the facilitators
lived in the community, they knew all the carers’ homes hence the facilitators accompanied the interviewer to the carers’ homes.

An ethical challenge that emerged from the recruitment of dyads, was the risk of coercion to participate. Firstly, we suspected that there was potential coercion during the recruitment as some individuals may have felt under some obligation to participate if approached by programme facilitators. It was even more concerning when the researchers learnt that the facilitators were local community members, having established relationships with potential study participants in the area. For example, one of the facilitators was a pastor’s wife and running a local crèche. It was highly probable that some individuals were members of the same church with the facilitator. We were concerned that some individuals were likely to feel obliged to participate in view of maintaining the existing relationship with the facilitator by not refusing to participate. Secondly, older carers knew their adolescent grandchildren participated in the HIV behavioural interventions.

- Is the 'lack of confidentiality between members' really an ethical issue in this study? If the two members of the dyad decided to share what happened in their interview then surely this wouldn't normally constitute a breach of confidentiality (if the information they share pertains to them)? You suggest in your Discussion that other authors may have written about this as an ethical issue in dyad research - if so, it would be good to describe the nature of that concern more broadly. If not, I would suggest taking out that paragraph.

RESPONSE: We have taken out that paragraph as we realised that it did not constitute breach of confidentiality when members decided to share between themselves the content of the interviews. We agree with the reviewer that this demonstrates the relative autonomy of participants to decide what they want to disclose on their own terms.

- The issue you raise in the section 'lack of understanding' (line 379f) is a serious one and requires much more elaboration, including referencing. I think you touch on two important issues here. One is an expectation of reciprocity - particularly important in the African research context, and an issue that is not foreign to ethnographers at all hence the suggestion that you refer to other ethnographic work. The second is the importance of trust, and a failure to respect or engage with reciprocity obligations may translate into a breakdown of trust, which could ultimately be harmful for research as a whole. I understand that in the research you conducted, you did not have funds or time to connect the carers to the appropriate services, but from how you have
written this paragraph, it sounds like you may have been uncomfortable with this. Considering that this is a methods paper, I think you need to be more straightforward and directive about how this issue should have been resolved, even if this includes a critique of your own work. To me, reiterating that explaining to participants that 'it's not my problem as a researcher to do this' seems wholly insufficient and, to be honest, rather disrespectful and a bit opportunistic. Are there other ways in which this issue could have been resolved? If you were to do the same research again (including planning the budget), how would you do this differently?

RESPONSE: In the results section, we have revised the heading as ‘expectations of benefits for research participation’ and elaborated on the challenges we encountered and stated how this could have been resolved:

Expectations of benefits for research participation

Spending extended periods of time with the same group of participants generated expectations of benefits among the participants for their participation in the study. As the participants were narrating their problems to the interviewer, they hoped for solutions from the interviewer. It was the older carers who had raised expectations of assistance, although one adolescent girl (C2) who was requesting for a loan on behalf of her grandmother (C1) to settle a financial debt as their lives were under threat. The older carers expected assistance with employment opportunities, food, housing, medication for arthritis and minor ailments, counselling, money, and adult schooling opportunities. It was interesting to note that the expectations of benefits were required to address their relational needs. For example, older carers repeatedly reported the challenges of caring for their adolescent grandchildren and their concerns of the adolescents’ risky behaviours. Poor communication between the older carers and the adolescents was also mentioned as a challenge. The older carers often requested the interviewer to intervene in strained dyad relationships and expected the interviewer to provide some form of counselling. Being caught in the middle of strained relationships between dyad members was stressful for the interviewer as she did not anticipate the magnitude of relationship problems yet could not help.

Several measures were taken address these concerns. First, all the participants were offered snack packs as a token of appreciation at every visit. The participants appreciated the packs as they would share the items in the family. Second, the interviewer continued to explain her role as a researcher not a therapist in accordance with the study protocol. However, to compensate for the researcher’s inability to help, participants were provided with a self-referral list with contact details of local service providers which they could contact for support and the responsibility to contact the service providers was left with the study participants. This raised an ethical concern that the information support that we provided for self-referrals was very difficult for our participants to then take forward in this setting. For many study participants, a lack of financial
resources was a barrier for them to access services due to related costs such as transport. Mostly older carers were non-literate and could not make phone calls, and others did not have access to telephones to contact service providers. Participants could not understand why the interviewer did not contact service providers on their behalf as they did not have resources to do so. We were concerned that participants were likely to lose interest in the study if they thought researchers were not supportive. Ideally, facilitating the linkage between study participants and the service providers would have been the best solution; but this had budgetary implications which were not covered in the study. Our strategy to spend more time explaining the role of research, emphasising its remit. This approach appears to have ameliorated misunderstandings, but it illustrates the challenges of conducting such relationally focused research in low-income settings.

- I don't really feel that your paper provided enough insight into the nuances of the dyadic method and the methodological challenges to support this particular conclusion "Therefore, the methodological and ethical challenges associated with a dyadic approach are not issues which can be resolved through the method. They are both a feature of the experience and a feature of the relational agency." I think you really need to explain this better. E.g. doesn't the dyad method specifically probe relational agency and relationships (see e.g. your argument for more dyadic research in line 73f)? I don't think you can both say that 'the dyadic method aims to study relational agency' and then say that any ethical issues that arise out of it 'are not to do with the method but with the relational agency'.

RESPONSE: We agree with the reviewer. We have amended our conclusion:

Therefore, the methodological and ethical challenges of the separate interviewing approach are associated with relational agency. They are both a feature of the experience and a feature of the relational agency. Rather than to try to design a method which resolves all these methodological and ethical dilemmas, it is important to recognise these challenges as features or characteristics of relationships and to illuminate that they exist. The challenges presented in this study displayed how things are experienced rather than them being the weaknesses of the method. They capture the essence of the experience of conducting a dyad study with adolescents and their older carers in our setting.

Minor comments:
- I like your use of 'negotiate' in relation to seeking informed consent (line 181) because this may be reflective of how one actually seeks consent for research. However, you may also open a can of worms and some readers may wonder what you mean by that. Perhaps you should consider changing 'negotiate consent' to 'seek consent'.

RESPONSE: We have changed ‘negotiate consent’ to ‘seek consent’.

- Line 189: conducting the interview 'in private' (not: in privacy)

RESPONSE: We have made the correction.

- Line 208: until that point, you say you focus on 'methodological and ethical challenges' so maybe add that to this sentence also.

RESPONSE: We have added ‘methodological’ to the sentence.

- Line 319 - 'they' should be 'there’?

RESPONSE: We have made the correction.

- Line 336 "Secondly, confidence was also secured through the practice of confidentiality by the interviewer" - I am not sure what that sentence means?

RESPONSE: We mean that participants’ confidence or trust in the confidentiality process of the research was enhanced through the interviewer’s conduct of adhering to the principle of respect for individual confidentiality by not disclosing information to the other dyad member. We have amended this for greater clarity in the manuscript.
‘Secondly, individuals’ confidence was also secured through the interviewer’s conduct of adhering to the principle of respect for individual confidentiality by not disclosing information between dyads’.

- Line 370: what does it mean that this was a 'longitudinal' dyadic study?

RESPONSE: We have removed ‘longitudinal’.

- Line 463 "unintended preferences of individual participants may have occurred" - I am not sure what you mean by that phrase?

RESPONSE: We agree with the reviewer that this phrase is confusing. To make it clear, we have revised the heading into ‘unintended preferential treatment of participants by researcher’ and elaborated upon its meaning in this context.

Unintended preferential treatment of participants by the researcher

While the interviewer spent a significant amount of time in the field to study the lives of the dyads within their naturalistic setting, unintended preferential bonding with individuals, particularly older carers, occurred. The interviewer established stronger rapport and more connections with the older carers, compared to the adolescents. Approaching older carers first and spending more time at the home waiting for the adolescents contributed to preferential bonding with the older carers. At every visit to the home, the interviewer had to first announce her presence to the older carers and to request permission to speak to the adolescents. Even when the adolescents knew the interviewer came to see them, they waited to be called by their older carers that the interviewer had arrived for the interview with the adolescents. Also, at the end of interviews with the adolescents, the interviewer had to announce her departure to the older carers. This is a social protocol in the area for home entry and home exit, and it is regarded as a symbol of respect to the elders or heads of families. As such, opportunities of interaction between the interviewer and older carers were greater than with the adolescents. During those interactions, the older carers always had important and interesting stories to tell the interviewer, also creating the need to follow-up their stories in subsequent visits. While extended time was spent with older carers and this generated detailed accounts about their worlds; however, it compromised adolescents’ voices as older carers’ views dominated the adolescents’ in the research process. Apart from complying with social protocols, our flexible interview structure
allowed for the interviewer to do the interview with any individual available between adolescents and the older carers. The interviewer also employed reflexivity as a tool to guide ethical practice throughout the study.

- Line 508-510: I am not sure what you mean with that sentence. Who would 'the audience' be in this case?

RESPONSE: We have clarified this by instead saying ‘about who will have access to their information’ and removed the term ‘audience’.

- Line 514 - 'because they were being protective'. When you introduced this issue in the main text, you were careful not to attribute a reason for why the adolescents did not reveal their older carer's HIV status. How do you know that this was the reason? It could also have been e.g. social stigma, or perhaps even an artefact of the age of the interviewer (it would be inappropriate to disclose such information across age lines). I would suggest taking this out here.

RESPONSE: We agree with the reviewer that our findings do not allow us to attribute a reason for why the adolescents did not reveal their older carer’s HIV status. We have now made reference to literature about what other authors have reported about single-sided account of experience between dyad members. We now state:

In this study, we found single-sided account of stories between dyad members when interviewed separately. For example, older carers disclosed their HIV-positive status, which their adolescent grandchildren were discreet about. This finding was also reported by Norlyk and colleagues (27) when they conducted repeated interviews with patients and their partners who were living with Parkinson’s disease. They reported that ethical and methodological considerations were intertwined when one partner address an issue of interest and the other not (27). Consistent with literature, our study was unable to probe the specific reasons for the adolescents to be discreet about their older carers’ HIV status as this may have breached confidentiality of older carers’ information. The boundaries of individuals were respected, because it was their decision about what and what not to share with the researcher (14). Drawing from the relational agency, adolescents’ actions are influenced by the nature of the relationship with their carers, and the actions are a product of that relationship. As mentioned, the relational agency explains how
adolescents' experiences are shaped by their relationships and how their behaviours are influenced by the relational agency. Being silent about their older carers’ HIV-positive status might also illustrate how care might be done in these cases, through discretion. This shows the importance of listening to both sides by having separate dyadic interviews. Dyad members may experience the same event differently; thus each individual’s story produces a dyad story, which in turn provides useful data to understand the dyad relationship. The fact of a single-sided account of a story reveals the nature of the relationship between individuals in the dyad. The implication of this tells us a little about how caring is bidirectional, but also can be hidden or not talked about for relational reasons. This methodological approach gives us valuable insights that may not have been revealed using a survey method or relying on only interviewing one individual within the dyad.

- I find that whole section (lines 512-522) somewhat speculative without contributing much substance to the discussion. For instance, I don't think it is quite clear how you understand the adolescent’s silence as being a product of ‘relational agency’ and this is also not clear from the main text. I would actually urge you to consider taking those lines out completely. Even the lines that immediately follow this section (e.g. 522-528) are difficult to follow, which could partly be because it presumes far greater knowledge of the project data than what was presented in the manuscript, so there to I would suggest either careful rewording or taking this out. If you decide to keep, then please bear in mind that the readers have not necessarily read a paper reporting on the main study results and so you will need to explain your insights in a bit more detail.

RESPONSE: Section deleted as advised.

- Line 543: what do you mean when you say that the challenges described ‘capture the essence of the experience’? Of which experience?

RESPONSE: We thank the reviewer for querying an incomplete statement which does not provide full details the experience we are referring to. We have now written the statement in full to indicate that we mean the experience of conducting a dyad study with adolescents and their older carers.
Jennifer Ilo Van Nuil, Ph.D. (Reviewer 2): The authors describe a range of the ethical and methodological challenges encountered during an ethnographic study using dyadic interviews with adolescents and older cross-generation caregivers. The challenges (both methodological and ethical) were combined in the findings and related to recruitment challenges, issues with the consent process, how to best maintain confidentiality, the implications and challenges of holding separate interviews, and the complex interactions between the interviewer and interviewees. The study from which the challenges were encountered took place in rural South Africa with six dyads (adolescent - caregiver) who were part of DREAMS initiative and involved multiple separate interviews as well as participant observation. To conclude the authors state that the challenges they encountered are actually features of the complex nature of the relationships.

I have three main comments and a few minor comments:

Depth - Findings and Management of Challenges: I suggest to add more about the experiences encountered and how it informed the challenges and management of such challenges, for some of the results discussed. For example, in lines 244 - 256 re sampling bias - did the researchers feel that there was sampling bias during the recruitment or was sampling bias more of a concern prior to the fieldwork?

RESPONSE: We have amended the Results section to add more details about our experiences and how it informed the challenges and management of the challenges. For example, we have clarified that the researchers anticipated potential sampling bias prior to the fieldwork due our recruitment strategy of recruiting potential dyads through the programme facilitators.

The potential participants were recruited through programme facilitators within an implementing organisation. We anticipated this recruitment strategy had potential sampling bias prior to the recruitment. The programme facilitators relied on their self-knowledge to identify potential participants as the facilitators were local community members themselves. Although this was an effective way of identifying participants, there was potential for bias about individuals that the programme facilitators chose to approach. Given that the study involved exploring participants’ experiences with HIV behavioural interventions, programme facilitators might have been tempted to lean towards inviting people who were thought likely to provide a positive account of
the organisation and the interventions than others. To reduce potential sampling biases, we worked with two different programme facilitators for each to identify two pairs of adolescents and their older carers. We also integrated a participant-driven sampling technique by requesting two adolescent participants to refer the researcher to other adolescent recipients in the care of older people. Having a small sample of participants who know each other in the neighbourhood raised further concerns about maintaining confidentiality of results. To keep the dyad partners’ versions confidential from each other, we only checked our interpretations with individuals, treating them as separate sources. To enhance anonymity and confidentiality of individuals, we needed to omit or slightly alter some distinguishing information, which could identify individuals from another (1). We did data omissions and alterations to balance the need to preserve both contextual issues and confidentiality (1). For example, information such as names of birth places, names of schools and church names were either omitted or altered. In addition, all participants were provided with a pseudonym to ensure confidentiality and to protect the privacy of the individuals.

Did the interviewer speak with participants about potential coercion (see line 259) or suspect that there was coercion during recruitment and how were these scenarios managed?

RESPONSE: The interviewer emphasized voluntary participation to the potential participants in view of reducing potential coercion by their partners and programme facilitators. The facilitators were also asked to introduce the interviewer to the potential participants; thereafter the interviewer took over.

The programme facilitator and the interviewer visited the individuals together at home for an introductory meeting; thereafter the interviewer was left with the individuals to discuss the study and to seek consent for the older carer and their adolescent grandchild in the absence of the programme facilitators. The interviewer emphasised voluntary participation to the adolescents in view of reducing risk of coercion by the older carers and the programme facilitators. All the six dyads approached, consented to participate in the study. There were no refusals or participants who withdrew during the study.
Were there any cases of unintended disclosure of information within the pair by the interviewer - how did this play out?

RESPONSE: No case of unintended disclosure of information within the pair by the interviewer occurred. We instead are highlighting the risk and the challenges in ensuring that this does not happen.

Or further, how was confidentiality maintained during dissemination, if findings were discussed with the participants or within the communities? Were these disclosure risks challenging to explain during consent when describing how information will be used and disseminated?

RESPONSE: We now state:

To keep the partners’ versions confidential from each other, we only checked our interpretations with individuals, treating them as separate sources. To enhance anonymity and confidentiality of individuals, we needed to omit or slightly alter some distinguishing information, which could identify individuals from another (1). We did data omissions and alterations to balance the need to preserve both contextual issues and confidentiality (1). For example, information such as names of birth places, names of schools and church names were either omitted or altered. In addition, all participants were provided with a pseudonym to ensure confidentiality and to protect the privacy of the individuals.

I think it is quite a different process to think about possible ethical and methodological challenges that might arise (based on literature and previous experiences) and then proactively make choices about the study conduct prior to starting the study than facing challenges during the study and having to adjust while the study is on-going. The latter are often the challenges that likely have not been identified in previous studies (unanticipated) and could be interesting for other researchers to consider when designing their future work (possible management strategies for discussion section?). It would be interesting if this were more clearly spelled out in the paper.

RESPONSE: We have indicated where challenges were either anticipated or unanticipated.
Scope - Reality of (Qualitative) Research: A few of the points raised in the paper are common to qualitative and other research more generally. If the authors could add more explicit linkage between the challenge described and the methodology, context, etc, then the link back to the main objective of the paper will be better maintained. For example, in many research situations, the consent process needs to be tailored to the individual person's needs. How is the process more or less (ethically or methodologically) complex? Another example is sampling bias, which is a concern in many studies that use programme facilitators for recruitment but what might be an interesting ethical and/or methodological conversation is about using participant driven sampling with a sample size of six pairs. How were the six pairs ultimately recruited into the study and what were the implications of that choice (e.g. if all the dyads knew each other because they were all referred from each other, how to maintain confidentiality of results).

RESPONSE: In the Results section, under the theme ‘potential sampling bias’, we now state:

The potential participants were recruited through programme facilitators within an implementing organisation. We anticipated this recruitment strategy had potential sampling bias prior to the recruitment. The programme facilitators relied on their self-knowledge to identify potential participants as the facilitators were local community members themselves. Although this was an effective way of identifying participants, there was potential for bias about individuals that the programme facilitators chose to approach. Given that the study involved exploring participants’ experiences with HIV behavioural interventions, programme facilitators might have been tempted to lean towards inviting people who were thought likely to provide a positive account of the organisation and the interventions than others. To reduce potential sampling biases, we worked with two different programme facilitators for each to identify two pairs of adolescents and their older carers. We also integrated a participant-driven sampling technique by requesting two adolescent participants to refer the researcher to other adolescent recipients in the care of older people. Having a small sample of participants who know each other in the neighbourhood raised further concerns about maintaining confidentiality of results. To keep the dyad partners’ versions confidential from each other, we only checked our interpretations with individuals, treating them as separate sources. To enhance anonymity and confidentiality of individuals, we needed to omit or slightly alter some distinguishing information, which could identify individuals from another (1). We did data omissions and alterations to balance the need to preserve both contextual issues and confidentiality (1). For example, information such as names of birth places, names of schools and church names were either omitted or altered. In addition,
all participants were provided with a pseudonym to ensure confidentiality and to protect the privacy of the individuals.

We have also added more details under the theme ‘consenting dyads’ to clarify how the process of informed consent was both ethically and methodologically complex and the strategies used to address complexities:

The process of consenting dyads was both ethically and methodologically complex. Differing needs of individuals in dyads challenged the provision for informed consent and assent during the process. The study information sheet was considered too long by some of the participants. All the older carers wanted the sheet read to them because they could not read themselves due to literacy skills or vision problems. Some non-literate older carers were not comfortable signing the consent form. In contrast, the adolescents did not want to spend the time reading the information sheet through and preferred the researcher explain it to them. They wanted the consent process to be accelerated to fit in with their limited time that they were willing to devote to the research given their competing commitments. As a result, we adapted the informed consent and assent process to the needs of individual dyad members such as reading or paraphrasing the sheet and the use of a mark in place of a signature on the consent document. However, rushing the process of informed consent raised the dilemma of being uncertain about participants’ full understanding of the informed consent. We ensured study information was presented to the study participants at every repeat interview and confirmed with the participants if they were still willing to continue participation in the study.

Discussion Considerations: Overall, the authors raise many methodological issues with this type of method but I would expect more elaboration, in the discussion section, on the larger ethical issues related to this type of research and how these issues fit in with other work done on both similar ethics topics and studies using this methodology. For example, what were the ethical implications of recruiting the participants in the way that was done, even though it may have been socially acceptable? How does the discussion on confidentiality link to other literature (lines 502-535) from other contexts? Ultimately do you think it was a good approach to use separate interviews?

RESPONSE: We have elaborated all the issues in the discussion and linked to the literature. By way of example, we show the amended discussion on recruitment and confidentiality:
As guided by the relational agency, recruitment strategies are influenced by relationships between dyad members and the socio-ecological context of the research setting. Researchers must consider the cultural values of the participants they intend to recruit (34). We recruited older carers first to align with socially accepted practices to engage with the caregivers prior to the young people. It was considered disrespectful to approach adolescents about participating in a research study without having first obtained permission from their caregivers. However, as others authors pointed out, this strategy may not address ethical concerns about risk of coercion to participate among vulnerable populations (4,5). Different approaches could be employed to deal with ethical dilemmas arising from recruitment of dyads. Young people can be approached first (5) or together with their caregivers (4). In Uganda, young people nominated their caregivers and provided permission for researchers to approach the caregivers (4). By requesting children to identify their caregivers, it eliminates controlling behaviours from researchers and facilitates children empowerment in research by giving them a choice and a voice in the selection of dyad members.

Confidentiality is one of the cornerstones of research involving human participants. Protecting research participants’ right to confidentiality is a responsibility shared by researchers, institutional review boards, and participants themselves. Interviewing dyads within one intimate relationship posed three confidentiality challenges in this study: limited trust in the confidentiality process, unintended disclosure of information by the interviewer, and right to access confidential information of the other dyad member.

One strength of separate interviews is that it allows participants more freedom to express their individual perspective than in the absence of their partner (26). Interviews with individual partners enabled them to reveal information to the interviewer while keeping it secret from their partner (e.g. pregnancy, sexual relationships). This enhanced our contextual understanding of the interpersonal relationships of dyads who kept secrets from each other (1). Yet, some participants had limited trust in the confidentiality process, regardless of being interviewed separately. They anticipated that their information could be shared with their partners hence they insisted on assurance for confidentiality. Our finding reflects those of Allan who also found that individuals will reveal confidential information if they are certain it will never be disclosed to their partner (2). In addition, relational agency states that individuals’ experiences are shaped and influenced by their relationships with others (33). An individual can have a sense of intentionally or intentionally influencing another person in a constructive or deconstructive way (35). In our study, the participants had a sense that if information was disclosed to their partners, this could influence their relationships in a deconstructive way. While the adolescents may be narrating
something to the interviewer, they sometimes appeared to be economising on what they disclosed to the interviewer perhaps because they are wondering about who will have access to their information. Certainly, in the first interviews, they may have wondered if they were speaking to the interviewer or speaking to their older carers by proxy as information might slip through the interviewer to the older carer.

Consistent with the literature, we found that, in separate interviews, participants expressed the desire to know what their partners said (25,26). A number of studies have begun to examine possible strategies for researchers to maintain confidentiality when conducting separate interviews with dyads (14,25). Our strategy reflects that of Zarhin (25) who also emphasized refraining from revealing information to protect participants’ confidentiality. In contrast to our strategy of reminding participants verbally about the confidentiality clause, Taylor and de Vocht (14) suggest incorporating this clause into the participant information sheets to make it clear to individuals that “no information shared by individuals would be disclosed to their partner.” However, attempting to be given the right to access information pertaining to their partners because of authority over the other is a relational issue. One’s actions and perceptions of self as an agent depends on the social and relationship context in which agency is enacted and experienced (35).

It might also be interesting for the authors to grapple more with their conclusion that the challenges are "features of the relationships between dyads rather than weaknesses of the dyadic approach" (line 561-562, also lines 537-543). If this is one of the main conclusions, then it might be worthwhile to go back through the paper and see where and how each finding section demonstrates this idea. If this idea was entangled within the findings, I think it would tie the piece together well.

RESPONSE: We have amended the discussion section to discuss important findings in the context of relational agency to show how the experience was shaped by relationships.

We acknowledge that our conclusion is confusing and have amended it to clarify the ethical and methodological challenges are a feature of the method (i.e. ethnographic and dyadic) and the challenges highlight the significance of relational agency and that confidentiality, reciprocity, trust and disclosure are all navigated through relationships.
Minor points:

- In the introduction, I suggest to include the ethical challenges that are specific to your topic, methods, etc. rather than the selection of ethical dilemmas in LMIC listed in lines 100-107.

RESPONSE: We have revised the whole introduction section and situated it in the context of ethical challenges that are specific to separate interviewing of dyad members.

Qualitative studies on dyads have increased (1) since the dyadic research approach emerged in the 1970s in marriage and family studies (2). The approach examines ‘the dyadic perception of reality, dyadic meaning, and dyadic being-in-the-world, in addition to the relationship component’ (1). For some research questions, interviewing dyads may generate data that could not be obtained from interviews with individuals (2). Scholars have used the dyadic approach in studies involving couples (2), caregivers and children or grandchildren (3–6) and patients and carers (7–10) in health research. For example, a Ugandan study examined care dyads of caregivers and HIV-positive young people about their experiences of disclosure of HIV status and the influence it had on their relationship (5). Different interviewing techniques have been used to collect data with dyads. The interviews can be conducted separately with each dyad member (11) or jointly with both members together (12,13). Separate interviews enable each individual to respond from their own perspective, ‘capturing the individual within the dyad, without forgoing the dyadic perspective’ (1), whereas conducting interviews jointly results in a shared narrative (14). A separate interviewing approach raises methodological challenges related to the method of conducting interviews with each individual member of a dyad and its influence on the data collected (14). Separate interviews can be time consuming for the dyad members and the researcher because two interviews are carried out (15). It also raises ethical concerns related to the personal relationship between dyad members when they are interviewed separately (16). Therefore, conducting separate interviews with dyad members could pose potential methodological and ethical problems that should not be overlooked.

Methodology and ethics are interrelated. Adherence to ethical standards can add to the value of research and, conversely, methodological soundness can strengthen ethics (17). In their editorial article, Knottnerus and colleagues (18) explain the link between methodology and ethics that ‘ethics of research methodology requires a methodology of research ethics’. Reviewing the ethics of research should consider whether the research questions are worth asking and if the methods used are an effective way of answering them (17). The approach of conducting separate interviews as a methodology has ethical implications as it critically influences data collection, interpretations of data and reporting of data.
Ethical issues arise in all aspects of research, and are particularly salient when studying vulnerable populations such as children and adolescents, the older people and people living with HIV or affected by HIV (19–21). Researchers have ethical responsibility of ensuring that individuals are given all the information needed to make informed decisions whether to participate in research or not. The process of respecting autonomy is rendered complex, given different conceptions of personhood (22). Most persons define themselves and make decisions within a wider network of social relationships (22,23). When engaging with an individual, one is in fact dealing with a complex relational web of persons who may include the immediate family, peers and significant others for whom the decision matters (22). However, to respect autonomy, Osamor and Grady (23) suggest researchers need to understand and respect relationships that are important to individuals and the process with which they incorporate the values inherent in these relationships into their decision-making. Adolescents may agree to participate out of obedience to or respect for their caregivers (19,20). For example, in a study to understand the resolution of discordance between adolescent-parent dyads about participation in research, Francis and colleagues (24) report that sometimes one individual in the dyad asserted authority over his/her partner about decision for participation.

Confidentiality is one of the cornerstones of research involving human participants. Protecting research participants’ right to confidentiality is a responsibility shared by researchers, institutional review boards, and participants themselves. However, combining ethnographic and dyadic approaches adds further complications to maintaining confidentiality of individuals within the same dyad. It is difficult to maintain confidentiality between the members of the dyad when information is validated, or when different versions are compared (1). The challenge of confidentiality also arises when reporting findings on the dyad as the amount of information that could identify dyad members could be more than in individual interviews (16). Separate interviewing has potential to generate anxiety within dyads because this approach might suggest that secrets exist, and that one person is willing to share these secrets with the researcher (and not with his or her partner in the dyad) (14). Individuals may express the desire to know what the other person in the dyad said, placing the researcher in an awkward position (25,26). The method of separate interviewing can confront the researcher with a dilemma of how to make sense of different versions of a story regarding events in individuals’ lives (11). Furthermore, in the face of competing accounts from individual interviews, the researchers are limited in their ability to probe further and ask direct questions, since in so doing, they may unintentionally disclose what the other individual said, thereby breaching confidentiality (11,25,27).
There may be an expectation of short and long term benefits and advantages to participation that influence individual consent and participation. This challenge may be greater when doing ethnographic work among vulnerable populations, because of the extended amount of time spent with participants (20). In a project with children and women affected by HIV/AIDS in Kenya, Nyambedha (20) found that the people in the area did not differentiate between activities of non-government organizations (NGOs), other researchers and his own study. Consequently, there were raised expectations that participation in the research could lead to interventions that would assist participants. Nyambedha argues that researchers can cause harm if no action is taken to address the high expectations participants may have.

As shown, researchers face complex questions of methodology and ethics in the application of a separate interviewing approach. These challenges are of a complex nature, yet dyad studies have received a relatively small amount of critical ethical and methodological attention (12,16,27,28), particularly in low-middle-income countries (LMICs).

In this article, we draw upon our own experience of conducting separate interviews in an ethnographic project with care dyads of adolescents and their older carers in rural South Africa and examine the ethical and methodological challenges which have arisen from our work and how these were addressed. We use these reflections to discuss some of the challenges and present possible management strategies that may be adopted in conducting dyadic health research in LMICs.

-Methods description: It might be good to describe the analysis process for the results presented in this paper instead of solely listing the analysis process for results which are not described within this paper.

RESPONSE: We have described the secondary analysis process for the results presented in this paper.

The first author kept a reflective journal in which she noted her experiences of the whole research process. The journal contained concrete descriptions of the interviewer’s experiences about ethical and methodological challenges emerging in this dyad study of care relationships between adolescents and their older carers and how these were addressed. All interviews were transcribed and translated into English. Transcripts and field notes were coded and managed
using NVivo 11. Following dyadic analysis, we examined themes emerging from each dyad member’s narratives (1) by assessing contrasts and overlaps between the individual versions. This paper does not aim to report on the substantive findings of this analysis, but rather we focus on ethical dilemmas emerging in this dyadic study of care relationships between adolescents and their older carers. We identified methodological and ethical challenges from these data during the thematic analysis.

-Line 301 - do you think this is a power dynamic or the nature of the caregiver/adolescent relationship or parenting style?

RESPONSE: We have revised and changed it to parenting style than power dynamics.

-Is it outside of the "norm" for dyads to share information they relayed during the interviews with each other outside of the study context (re lines 368-376)? I would imagine that it would be good if the ideas from the interviews opened a dialogue between the caregiver and the adolescent, outside of the study. I ask because I am curious. If it is a known part of the method, is this really a challenge?

RESPONSE: We have taken out that paragraph as we realised that it did not constitute breach of confidentiality when members decided to share between themselves the content of the interviews.

Maureen Kelley (Reviewer 3): Review comments BMC "Are you going to tell my grandmother that I am pregnant?": Ethical and methodological challenges of research with adolescents and their older carers in rural South Africa"

Thank you for asking me to review this paper. This is a valuable and very interesting ethnographic, research ethics study on an area of growing interest in dyadic health research
across generations. As the value of such research is increasingly recognized for addressing health needs for children, adolescents, and older adults the authors rightly argue as a starting point that one cannot accurately investigate health and social needs in isolation of the social context of these intergenerational caring relationships, nor should these important relationships be ignored. However, studying individuals within and across relationships poses a number of ethical and methodological challenges for research design, practice and oversight. While there has been some work to identify these challenges, this study offers greater depth to our understanding of the specific challenges raised when studying child-grandparent dyads, a caring relationship of increasing significance in LMICs with high rates of "skip-generation" households. It also suggests ways of responding to these challenges, but this aspect is understated and could be strengthened.

Some light editing is needed to catch a few missing prepositions and other grammatical typos here and there, but otherwise it is clearly and nicely written. I enjoyed reading the paper.

Specific comments:

It is always a little tricky to present research ethics data as a secondary analysis of a primary clinical or social science study without risking some confusion in the reader by conflating the rationale, methods and findings of the primary outcomes under study with those of the research ethics/challenges analysis. This paper navigates this balance fairly well but could use more explicit sign-posting in the background and methods sections to more clearly distinguish the primary study design from the research ethics/methodological challenges analysis. For example, I take it that relational agency as a theoretical framework informed the primary study but did it also inform the research ethics analysis at all? If so, how? (For example, potentially it helps illuminate the tensions in traditional approaches to consent and confidentiality. Is it also doing work to inform the view that we not see these challenges as limitations to dyadic research but rather inherent features in complex relationships?) I would include more in the methods-analysis section to explain the analytic approach for the secondary analysis.

RESPONSE: We have revised the introduction section and situated it in the context of ethical and methodological challenges that are specific to separate interviewing of dyad members. Also, we have revised the methods section and described the secondary analysis process for the results presented in this paper instead of exclusively describing the analysis process for the primary study.
We have made it explicit that relational agency informed both the primary study design and the research ethics analysis. We now state:

The theoretical framework of relational agency informed the research question, methods and interpretation of findings.

A significant strength of this paper is that it includes both challenges and ideas for potential solutions. The results section includes descriptions of what was done to respond to the challenges, and these strategies are considered in the discussion section. I would encourage the authors to frame this paper at the outset as doing both. Places to frame as including both challenges and solutions: title, abstract, last para of background (line 129), introduction to results section.

RESPONSE: We agree with the reviewer, and have now framed this paper in the beginning as presenting challenges and solutions.

In this article, we draw upon our own experience of conducting separate interviews in an ethnographic project with care dyads of adolescents and their older carers in rural South Africa and examine the ethical and methodological challenges which have arisen from our work and how these were addressed. We use these reflections to discuss some of the challenges and present possible management strategies that may be adopted in conducting dyadic health research in LMICs.

Background section, line 102: Perhaps better to only list the specific issues in the research ethics literature that are relevant to understanding the issues arising with dyad studies involving children/young people and carers. This establishes a more precise starting point in the literature for the research ethics issues being raised here. Starting with the range of ethical issues discussed in LMIC research ethics literature is very broad indeed - e.g., I don't see how the capacity of ethics committees is relevant to the findings of this study and is never mentioned subsequently in the paper. Whereas the literature on navigating confidentiality in household research and HIV-testing research with couples, is directly relevant.
RESPONSE: Thank you for this suggestion. As previously mentioned, we have revised the introduction section and situated it in the context of ethical and methodological challenges that are specific to separate interviewing of dyad members.

Methods section, lines 142-43: To clarify, consider revising slightly to say that "the concept of relational agency informed the research question, methods and interpretation of findings." (But see comment above - would help to include a more explicit account of how that theoretical approach informed the methods in this secondary analysis.)

RESPONSE: As mentioned above, we have made it explicit that relational agency informed both the primary study design and the research ethics analysis.

The theoretical framework of relational agency informed the research question, methods and interpretation of findings.

Results section: The current organisation of the results section mixes methodological and ethical challenges, moving back and forth between these, which can be confusing. I would consider grouping by methodological and ethical issues separately as a clearer way to inform future study design and ethical planning. (As you do in part of the discussion section: "This study discussed four confidentiality challenges emerging in separate dyadic interviews with adolescents and their older carers…"). Alternatively, keep the current structure but indicate more clearly whether each is a methodological vs. ethical challenge (or mixed).

RESPONSE: In the results section, we have now indicated whether each challenge is a methodological, ethical or mixed challenge.

Results, line 219: It would be helpful to include one or two sentences to set up the results section with an overview of findings and how these are organized.
RESPONSE: We have added a short paragraph to set the scene of theme emerging in the analysis of ethical and methodological challenges and how these are organized.

Information recorded in the first author’s journal highlighted several ethical and methodological challenges which guided the choice of the following themes: recruitment of dyads, consenting dyads, confidentiality, separate interviewing of dyads, and interviewer-dyad interaction, and how these challenges were addressed in the study. It must be noted that some challenges were a combination of both the method and ethics. We have thus indicated whether each challenge is a methodological, ethical or mixed challenge.

Results, line 244: Is the problem of sampling bias described here due to the dyadic nature of participant recruitment (and thus likely to be a challenge in any dyadic recruitment strategy) or was the problem of selection bias due to limitations of the DREAMS adolescent database, or some other factor in the DREAMS recruitment strategy not unique to dyadic studies? This strikes me as something to list in the limitations section of the primary study, but not obviously a methods challenge to report in this secondary reporting of challenges in dyadic studies.

RESPONSE: We have explained that using the programme facilitators in the recruitment of dyads raised concerns of sampling bias. We take the reviewer’s suggestion to list the problem of selection bias as a limitation. We now state:

The potential participants were recruited through programme facilitators within an implementing organisation. We anticipated this recruitment strategy had potential sampling bias prior to the recruitment. The programme facilitators relied on their self-knowledge to identify potential participants as the facilitators were local community members themselves. Although this was an effective way of identifying participants, there was potential for bias about individuals that the programme facilitators chose to approach. Given that the study involved exploring participants’ experiences with HIV behavioural interventions, programme facilitators might have been tempted to lean towards inviting people who were thought likely to provide a positive account of the organisation and the interventions than others. To reduce potential sampling biases, we worked with two different programme facilitators for each to identify two pairs of adolescents and their older carers. We also integrated a participant-driven sampling technique by requesting two adolescent participants to refer the researcher to other adolescent recipients in the care of older people. Having a small sample of participants who know each other in the neighbourhood raised further concerns about maintaining confidentiality of results. To keep the dyad partners’
versions confidential from each other, we only checked our interpretations with individuals, treating them as separate sources. To enhance anonymity and confidentiality of individuals, we needed to omit or slightly alter some distinguishing information, which could identify individuals from another (1). We did data omissions and alterations to balance the need to preserve both contextual issues and confidentiality (1). For example, information such as names of birth places, names of schools and church names were either omitted or altered. In addition, all participants were provided with a pseudonym to ensure confidentiality and to protect the privacy of the individuals.

Results, line 259: The authors begin: "Another dilemma emerging in the recruitment of dyads was a risk of coercion to participate." Since this is the first ethical issue mentioned in results (the prior section described a methodological issue) I would say, "An ethical challenge that emerged from recruitment of dyads, was…"

RESPONSE: We have made the correction.

Results, line 275: How are the challenges of contacting adolescents in the dyad a special challenge for dyadic studies? Isn't this just a general challenge in recruiting mobile, busy participants, especially adolescents? Rather than a challenge, dyadic studies with grandparents may offer the advantage of having an "anchor participant", the grandparent, who can help you track down their grandchild. Isn't the issue, rather, of getting both of the participants in the dyad in the same place for the joint interviews?

RESPONSE: We feel this is a special challenge for dyadic studies. Unlike individual studies whereby once an individual has been contacted and agreed to participate in the study, then the interview can proceed. In this dyad study, both members had to be first contacted and invited for participation prior to consenting and interviewing. Failure to contact one member delayed the research process. Therefore, this was still an issue for separate interviews.

Results, line 462: Do you mean unintended preferential treatment of participants by the researcher? If so, I would suggest revising this header to say more clearly what this section captures.
We have revised the heading as ‘Unintended preferential treatment of participants by the researcher’ and elaborated on the challenges we encountered:

Unintended preferential treatment of participants by the researcher

While the interviewer spent a significant amount of time in the field to study the lives of the dyads within their naturalistic setting, unintended preferential bonding with individuals, particularly older carers, occurred. The interviewer established stronger rapport and more connections with the older carers, compared to the adolescents. Approaching older carers first and spending more time at the home waiting for the adolescents contributed to preferential bonding with the older carers. At every visit to the home, the interviewer had to first announce her presence to the older carers and to request permission to speak to the adolescents. Even when the adolescents knew the interviewer came to see them, they waited to be called by their older carers that the interviewer had arrived for the interview with the adolescents. Also, at the end of interviews with the adolescents, the interviewer had to announce her departure to the older carers. This is a social protocol in the area for home entry and home exit, and it is regarded as a symbol of respect to the elders or heads of families. As such, opportunities of interaction between the interviewer and older carers were greater than with the adolescents. During those interactions, the older carers always had important and interesting stories to tell the interviewer, also creating the need to follow-up their stories in subsequent visits. While extended time was spent with older carers and this generated detailed accounts about their worlds; however, it compromised adolescents’ voices as older carers’ views dominated the adolescents’ in the research process. Apart from complying with social protocols, our flexible interview structure allowed for the interviewer to do the interview with any individual available between adolescents and the older carers. The interviewer also employed reflexivity as a tool to guide ethical practice throughout the study.

Discussion, line 490 and following: "In our study, we approached older carers first to align with socially accepted practices." Referring back to your last results sub-section, do you think approaching grandparents first and spending more time at the home waiting for the adolescents contributed to the last challenge mentioned, preferential bonding with the grandparents? Is that the challenge you have in mind here in referencing the Ugandan studies? It might help to clarify which specific challenges the Ugandan model is meant to address.
RESPONSE: We have started by clarifying factors which contributed to preferential bonding with the grandparents, in the results section, as shown above.

Referencing the Ugandan studies was meant to link our experiences to the literature about how the authors used different recruitment strategies for dyads and how they structured separate interviews with dyads. We now state:

Different approaches could be employed to deal with ethical dilemmas arising from recruitment of dyads. Young people can be approached first (5) or together with their caregivers (4). In Uganda, young people nominated their caregivers and provided permission for researchers to approach the caregivers (4). By requesting children to identify their caregivers, it eliminates controlling behaviours from researchers and facilitates children empowerment in research by giving them a choice and a voice in the selection of dyad members.

Discussion, line 516 and following: "As mentioned, the relational agency explains how adolescents' experiences are shaped by their relationships and how their behaviours are influenced by the relational agency." Considering the framework of relational agency, there is no mention of other relationships outside of the dyad under study - the grandchild/grandparent. In the team's experience, were there possible blind spots regarding other important relationships in either the adolescents' or grandparents' lives, such as peers, friends, other family, whose influence was important to understanding the full picture of health and social issues under study, but which are excluded when limiting to study of the dyad, as opposed to family, household or community? The dyad is still only capturing two points of connection in a complex relational web, all impacting relational agency, social well being and health.

RESPONSE: Adolescents and indeed the older people had relationships with other people too, which were significant in shaping their lives. They were part of a complex relational web. For example, adolescents' lives were linked to their parents, friends, and relatives. However, we did not explore how their experiences in data collection and ethics processes were influenced by the relationships with others.