BMJ Open

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Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-016072
Article Type:	Research
Date Submitted by the Author:	25-Jan-2017
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Primary Subject Heading:	Global health
Secondary Subject Heading:	Mental health, Public health, Qualitative research
Keywords:	PERINATOLOGY, PRIMARY CARE, Anxiety disorders < PSYCHIATRY, PUBLIC HEALTH, QUALITATIVE RESEARCH

Title: Domains of the pregnancy-related anxiety scale: A phenomenological approach

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Keywords: Pregnancy-related anxiety; anxiety; women's health; pregnancy; global health

Word count: 4,677

ABSTRACT

Objectives: To explore and understand the experiences and priorities of pregnant women living with pregnancy-related anxiety in Mwanza, Tanzania.

Design: Descriptive phenomenological approach.

Setting: Two clinics in the Ilemela and Nyamagana districts of Mwanza.

Participants: Pregnant and postpartum women who obtained high scores on a PRA scale during pregnancy in a larger quantitative study were contacted to participate in an interview (10 women, aged 18-34 years; 3 HIV positive).

Measures: Semi-structured interviews were undertaken, with guiding questions related to the women's experience during pregnancy. The Colaizzi method was utilized with transcipts that had been translated and back-translated from Swahili to English and then hand-coded by the interviewer, with independent review by another researcher to verify the analysis.

Results: PRA, as experienced by women in Mwanza, was a state of worry and concern, often causing physical symptoms, and disrupting personal sense of peace. While some themes in the women's experiences reflected the domains examined in the PRA scale used to identify potential participants, others such as lack of knowledge, partner relationship, interactions with the health care system, spirituality, and fear of HIV/AIDS were otherwise missing. Their prominence in the participants' stories broadens our understanding of PRA.

Conclusions: The realities and viewpoints of women in LMIC experiencing PRA are still relatively unknown. The findings from this study provided much-needed insight into the perspectives and priorities of women in Mwanza who have experienced PRA and support the need to further explore this phenomenon in other LMIC. The additional domains identified

reinforce the need for a PRA tool that will accurately and adequately capture the complexities of PRA for women in this region.

ARTICLE SUMMARY

Strengths and limitations of this study

- Partnerships with the local university in Mwanza allowed involvement and collaboration with local health professionals in the development of the method, recruitment, and data collection processes.
- Extensive international clinical and research experience by the researcher and supervisor was instrumental in creating relationships and opportunities to ensure that the voice of the patient was heard and that local context and culture was incorporated into the data collection and analysis process.
- This is the first qualitative study of the experiences of women who have experienced PRA in Tanzania.
- The exclusion criterion was amended to include early postpartum women as many women from the associated quantitative study began to deliver before recruitment had been completed. While we acknowledge this alteration in the study design as a potentially significant limitation, postpartum women demonstrated the ability to draw from their experience during pregnancy and their stories were rich with detail.
- The stigma of mental illness and presence of a local third party (translator) may have affected the level of participation, engagement, or willingness of women to participate in the interviews.

- Due to time constraints, it was not feasible to return to the participants to present initial findings and collect feedback, as per Colaizzi's method.

INTRODUCTION

Pregnancy-related anxiety (PRA), as determined from research in many high-income countries, has been strongly linked to preterm births, pregnancy complications, and negative infant outcomes.[1-9] PRA, a distinctive syndrome, encompasses specific dimensions that distinguish it from depression, stress, or generalized anxiety.[10, 11] These dimensions include fears and worries about the health and survival of the unborn child, having an 'abnormal' baby, the birthing process, developing medical problems during pregnancy, and ability to parent and care for the infant following birth.[10-16] There has been little exploration into women's experience of PRA.

In 2012, women in LMIC had a 1 in 150 risk of dying from complications in childbirth or pregnancy; this was in sharp contrast to a risk of 1 in 3800 for women in high-income countries.[17] In 2012, Canada reported 555 infants deaths due to complications from preterm birth, which is the greatest cause of neonatal deaths globally, whereas Tanzania reported over 17,000.[18] The presence and impact of PRA will be even more pronounced in LMIC given the high maternal and child mortality rates, poverty, and lack of resources. The realities and viewpoints of women in LMIC experiencing PRA are still relatively unknown as only one qualitative study explored antenatal mental distress in Africa.[19] The study, undertaken in Ethiopia,[19] explored the broad phenomenon of antenatal mental distress rather than the more specific focus of PRA.

Attempts to transfer evidence from high-income countries to inform programs or initiative in LMIC, without alterations for cultural and contextual relevancy, have often proven to be

unsuccessful, if not problematic.[20] In an effort to address the lack of knowledge about PRA in LMIC, this study explored the concept of PRA through the lived experience of pregnant women living in Mwanza, Tanzania. We present major themes in the participants' stories that did not reflect the domains of the PRA scale as it reflects the range of anxiety symptoms experienced by pregnant women in LMIC. We incorporate culture and context to understand the meaning given by the participants to the PRA experiences that have taken place.

METHODS

Women's experience of PRA was explored through the Husserlian lens of descriptive phenomenology[21-23] rather than a Heideggerian interpretive approach.[21] As such, bracketing permitted the reduction of the experience to the essence of PRA as it was experienced by women in Mwanza, free from conscious interpretation and influence of the researchers.[21-23] Important elements of the participants' experiences—gender related inequities, low literacy, low education, and lack of decision-making authority—were clarified through field notes and peer debriefing.[23, 24]

Setting and participants

The study sample was obtained from a quantitative study underway to examine the individual and collective contribution of PRA and depression in the prediction of preterm birth and postpartum depression.[25] Purposive sampling was employed to identify women (a) 18 to 34 weeks' gestation, (b) able to speak English or Swahili, and (c) had high scores on the PRA scale. Eligible scores from the PRA were determined using Fairlier et al.'s[26] recommendations of three or more responses indicating high anxiety. As research staff reviewed records of women

enrolled in the quantitative study, they identified and contacted eligible participants. The potential pool of participants was smaller than anticipated, as contacting women after they had left the clinic proved challenging and women began to deliver. Through a consultative process with the research team of the quantitative study, and approved by ethics, the sample included pregnant and postpartum women with high-anxiety with three or more responses indicating high anxiety, two high anxiety and at least two moderate anxiety responses, or one high anxiety and at least three moderate anxiety responses. Recruitment was ongoing as interviews took place; repetition of discovered information and confirmation of data that had been previously collected was achieved after 10 interviews, indicating data saturation.[27]

The study recruited pregnant women from antenatal clinics in the Ilemela and Nyamagana districts of Mwanza, Tanzania. The clinic provided care to 40 to 50 women daily; 40% of these women deliver at hospitals and health centres that provide maternal and child health and delivery facilities.[25]

Data collection

A research associate inquired via direct telephone interaction, using a standard script in Swahili, about women's interest to participate in an interview in a private room at the antenatal clinic that they were familiar with. During the face-to-face contact, details about the study including purpose of study, time commitment, risks, benefits, privacy, consent, and voluntary nature of participation was shared prior to obtaining informed consent. A trained interviewer (MKR) conducted semi-structured interviews in the clinics in Mwanza from October to November of 2014. The interview guide (Appendix A) provided general questions to direct participants in a

uniform manner; interviews were also participant directed and the interviewer took cues, probed, and requested further detail based on the information that was shared. Interviews were 40-75 minutes long, and were (a) conducted with the help of a Swahili translator, (b) audio-recorded with permission, (c) transcribed in Swahili, and (d) translated to English and back-translated to Swahili to ensure language equivalency. Field notes were maintained throughout the study and used to complement the interview data and emphasize the essence of the participants' experiences of PRA. Other sources of data included demographic information about the participants, which was obtained from the larger study to reduce participant burden.

Analysis

The Colaizzi method, with the exception of the final step of validating data with the participants, guided the analytic process.[27, 28] Each audio recording and transcript was reviewed numerous times while reflecting on field observations (e.g., facial expressions, gestures, disposition).[27] Bracketing continued during this process to set aside beliefs, preconceptions, and values and be fully immersed in the participants' descriptions. Significant statements and phrases that pertain to PRA were identified, extracted, compiled into a separate document, reviewed, and associated with a formulated meaning and assigned to a broad category, or theme.[27, 28] A second researcher (SP) verified the process and ensured consistency in the meanings derived from statements, referring to the raw data as needed.[29] Formulated meanings associated with each significant statement were organized into categories or unique structure of clusters of themes and incorporated together to create a specific thematic impression.[27, 28] After merging all themes, a thematic map was compiled and an exhaustive description of the phenomenon of PRA in

Mwanza, Tanzania was detailed.[27] Pseudonyms were utilized, as well as participant numbers correlating to the quantitative study.

Triangulation of qualitative data against the 10-items on the PRA scale enabled examination of the phenomenon of PRA from multiple perspectives.[30, 31] An additional method of triangulation, peer debriefing, prevented bias and allowed alternate points of view to emerge in the understanding of local context and culture.[24] Peer debriefing occurred with the interpreter, members of the community, employees and students at the Catholic University of Health and Allied Sciences office, and community members, including shop keepers, taxi drivers, and neighbours. Although we confirmed the PRA scale correctly identified these participants as experiencing the phenomenon under exploration, additional domains of PRA were also identified. Their prominence in the participant stories is important in broadening the understanding of the phenomenon of PRA. We present these additional domains of PRA in the findings.

Limitations

Enrolling women in postpartum period did not overly influence their ability to recall the experience of PRA as evident from the richness of the stories. Women were reminded and encouraged to reflect only on their experience during pregnancy. The presence of a translator and stigma attributed to 'mental illness' may have affected the level of participation or engagement in the interviews.[32] The inability to return to the participants to validate the study findings is also acknowledged as a limitation.

RESULTS

All of the women were residing in semi-urban areas, urban areas, or rural areas with reasonable access to semi-urban centers in Mwanza. Women were aged between 18 to 34 years of age. Of the 10 women, 4 were pregnant at the time of the interview and 6 had already delivered. Seven of the women (70%) were multiparous, and 2 had previously experienced the death of a child. Most of the women (90%) indicated that they were married or cohabitating with the child's father. Three of the women were HIV positive. Levels of education varied from no schooling to higher levels of basic education.

Five themes did not reflect domains of the PRA scale: knowledge and understanding, partner relationships, interactions with the health care system, spirituality, and fear of HIV/AIDS.

Knowledge and understanding

Lack of knowledge, or understanding of what was *normal*, was an underlying issue in many of the worries participants had about pregnancy and taking care of a new baby. Berta disclosed

> I get frantic at times because I know that my knowledge and understanding of what a baby might be suffering from in low. Currently she is active in my belly. But when she is born, she might cry at night and there is no one to help me learn what might be wrong with her. Mostly I will guess. But for the days and nights now, I worry what could happen to her because of me.

Margaret found herself asking people around her about symptoms she was experiencing. "For instance, last week I had very severe abdominal pain for about 3 hours; I could not sleep. People

tell me that it is a normal situation." Neema experienced heightened anxiety as she could not understand her somatic symptoms explaining

> I felt bad and I was ill. About my health, after seeing myself very thin since I was so often ill, though it [was] for all my pregnancies but in this one it was severe with a lot of stress…The felling of body weakness and fatigability went throughout the pregnancy.

Both Neema and Margaret experienced symptoms that they feared might be attributed to HIV and were terrified that this might be the cause of their symptoms. Margaret "fail[ed] to eat" and was "vomiting a lot," while Neema "felt ill", became "very thin," and was overcome with "weakness", all of which contributed to the fear of having HIV. Neema explained "I was tested when I was about 8 months pregnant for HIV infection and I was fine, I was not infected. But all those months, I thought I was." Although both were tested and received results that they were not HIV positive, their lack of knowledge of common somatic symptoms of pregnancy caused significant distress.

Partner relationships

Grace described the support her partner provided after she and their first child was diagnosed with HIV as: "[he] didn't disturb or humiliate me as for why he has no AIDS and we do, he accepted us." Grace kept on thinking of the current pregnancy "if all my children will be infected how things would be. Even when I rest for a few days, about 3 or more days then the concerns keep on coming back." Neema candidly shared the worries caused as result of her husband:

> I don't know what was the issue but they say some might hate you when you are pregnant, I thought that was the reason. When you are in such situation and he comes asking for sex, it is an issue. It was very difficult for me…maybe because he found me

> often sick, maybe he was hurting inside…happiness diminishes, love fades away. I thought he might have been seeing another woman. I don't know, but at the late stages of my pregnancy be became close, he changed and that was a relief.

There were participants who had longed for emotional support from their partners but were unable to obtain it. Grace's husband travelled frequently; she explained "as his work is that he has to travel…he is often not at home…he does not stay at home most of the time. So it is not easy to tell him what happens to me every day." Berta explained that at one point in her pregnancy, "My partner took me to my parents' place and left me there. No one would talk to me without my husband there. Even visitors would only talk to my father. It was not like they were coming for me, or to know how I feel or how I was doing. They had no time to ask all that." Conversations with research associates revealed that women in Tanzania (or Tanzanians in general) often do not discuss personal concerns with friends, or even family. Once Berta returned from her parents' place, she explained "During that time [pregnancy] my husband was not around, he had travelled. We had poor communication when he was away. Whenever I called, he was not reachable. At the time he was away, I was already confused because [of] my situation and I needed him… but at the time I couldn't get through to him, I was very worried during that time."

For participants in this study, the notion of *support* was contextually and culturally defined as financial support as gleaned from peer debriefing. Aisha had moved to Mwanza from her rural hometown, where weeks passed since her partner left. Aisha had little contact with the father of her unborn child, and received little help when he did respond. "What gave me worries

was…there were times I…asked for support and he wouldn't help me." Aisha had moved to Mwanza from her rural hometown, where weeks passed since her partner left. She recalled, "During that time, when it happens that I face financial issues and I ask him for help and he [father of the child] doesn't respond, I was just ... crying. What if I needed medicine?"

Interactions with the health care system

All participants in this study received antenatal care at least once during pregnancy. Margaret shared "I am used to calling the nurse whenever I get worse, I meet her and she helps me." Margaret would "do whatever the doctors instructed [her] to do" and found "I feel peace whenever I go to the hospital, since [she] gets advice from them to be well and keep [her] baby well." Joyce also recalled positive interactions with health care providers; however, "what I see is, they [health care providers] are more supportive in this pregnancy, especially the nurses. Whenever I face a problem they advise and help me." However, some women experienced less favourable interactions. Berta recalled a stressful week in which numerous providers contradicted her diagnosis of "low blood" (a common term used to mean anemia—often women will know this phrase in English without the need for translation) and informed her "that I might fall down or deliver a dead baby or that is how all of my reproduction will be." The worry in her voice and the expression on her face depicted even more than her words. Her voice grew shaky, her eyes began to water, and she fidgeted with her hands in her lap. Berta felt as though the interaction with health care providers had exacerbated her worries explaining:

> So she didn't give me clear information or encourage me. I felt like she was adding on my problems since when I was trying more to get information from her, she said 'There is this lady who came here with the same situation as yours'; I directed her, so let's find

her, she can give reliable information. So herself as a nurse who was just advising me on my issue couldn't know where I could get help. So I fel she added on me a load in my thoughts.

Neema described a particularly difficult day in which she had arrived very early at clinic for assessing high blood pressure. Reflecting on the process of taking number to receive service she shared:

> I came early and I was ill on that day. I was the 4th lady to arrive. At a time we were provided with numbers I never knew, I had gone to the toilet and there were about 99 women in queue. I missed the number. The nurse refused to give me a number saying 'you were not around, there are people who were here early, you came late and you want number.' I shed tears, I was upset and sad, I felt bad and I was ill, I went into the room where they take physical measures.

Sarah had waited a long time to become pregnant thus when the time finally came, "I wished to see my stomach grows fast. I used to check up on myself every now and then I felt like my stomach was not growing, so I felt worried...if the child was alive inside my womb." Sarah described frustration in being advised to stay on bed rest after experiencing bleeding in the first trimester. She stated, "I don't want to take the bed rest, though they advised me to, I figured out that I couldn't because I am working…I don't have much time to stay at home [considering that] I would have to take maternity leave after delivery. I was so worried, I was frustrated. That was very hard for me." While routine prenatal care was provided free of charge in Mwanza,[25] strained relationships with health care providers, the inability to access additional services or lost time at work, was an underlying issue in many of the narratives.

Spirituality

The women's spirituality permeated many conversations, often woven among the fears and concerns they expressed. Imara had 3 girls and felt worried as her sister-in-law's wanted their brother to marry another women who may be able to give birth to boys. She explained how her belief in God helped her to "take heart" (i.e., took courage) by thinking:

> God is the one who provides, it is not like I am going to the market, that I choose I want this and that, no, I encouraged myself that God is the provider you can't say that I have only girls,…I believe God knows more and I don't.

Wema's "biggest worry was death" because "I was swollen all over the body, especially my feet and it was painful all over…the doctor I was advice, there were no any other cause except for the pregnancy. Wema's sister-in-law died from pre-eclampsia. When asked how she managed to cope with her worries, Wema simply replied, "I only prayed to God…I just pass through; it reach a point I had to take heart, thought it was God's plans." Similarly, Berta believed that "God is the one who knows it all..." including her own future and if she "will deliver safely or not." Despite her struggles, Berta "was encouraged by being thankful to God in everything." Sarah had experienced particular anxiety that her stomach was not growing large enough to indicate that a healthy child lay inside. For Sarah aside from her husband "Honestly, my other help was from prayers only. When I pray I get peace of mind. I stopped worrying. I believed my stomach would get larger. So as much as we talked and prayer, I felt peace."

Fear of HIV/AIDS

Fears of HIV/AIDS consumed the thoughts of the pregnant women who could not explain their somatic symptoms. Margaret explained that, "I was vomiting a lot, not eating well, it made me have poor health and I became very thin. So I was thinking, I had not tested [for HIV] and I was very worried." She described feeling scared "after seeing myself very thin, though it [was] for all my pregnancies but in this one it was severe with a lot of stress…" Neema, who also saw herself feeling thin and unwell, described:

> It was during my early pregnancy but the feeling of body weakness and fatigability went throughout the pregnancy, I was tested when I was about 8 months pregnant for HIV infection, I was fine, I was not infected. My worry was because I was often sick and had lost weight so much, so event that added in my thoughts.

The three HIV positive women had relatively recent diagnoses – within the past three years – were preoccupied with worries about their unborn child/infant, and concerns for their child's future if they were to pass away. Grace talked about her reactions to her HIV positive diagnoses:

> I was frightened and full of worries. I passed about three days without food since I had a lot of stress and thoughts, I was sad, I was worried and I cried so much. I never expected my baby be infected or even myself; I never knew until I became pregnant again and I found out that I was HIV infected together with my oldest child.

Grace also discussed her concerns about the antiretrovirals that she began taking during her pregnancy and their impact on her unborn child. She explained:

> Those drugs were bringing me different conditions [side effects]. I felt like dizziness and was thinking was these drugs to protect the child who was in my womb? If they make me

feel this way, and in other days, I even lack sleep, with these conditions will my child be alive? Will the drug help me? I was worried.

Joyce's initial "concern was perhaps my child would also get infected, I asked the doctors, they reassured me and I stopped worrying." However, the initial reassurance faded as she considered her own diagnosis and then explained, "Both of my parents died and relative from my husband's side know nothing…I am worrying of delivering a baby who is HIV infected and was wondering what if I die early, who would I leave my baby with?"

DISCUSSION

The PRA Scale[11, 16] has been identified as an appropriate tool for examining the experience of PRA for women in high-income countries.[33] Nonetheless, there have been claims that this tool, along with others designed to examine this phenomenon, displays relatively narrow domains that may not reflect the essence of PRA experienced by women.[34] Our study confirmed this assertion for women in LMIC, specifically in Mwanza. Lack of knowledge, partner relationships, interactions with the health care system, spirituality, and fear of HIV/AIDS are suggested as additional domains based on their strong presence in the narratives and themes derived from the participants' stories. Table 1 provides suggestions for associated prompts related to each of these domains based on the participants' stories. These prompts together with the PRA scale may assist in the development of a comprehensive measurement scale that will more accurately depict the sociocultural context of life in LMIC, specifically Mwanza, and therefore more accurately assess and identify pregnant women who are experiencing PRA in this region.

Table 1. Additional domains of pregnancy-related anxiety as detailed by participant narratives in Mwanza

Additional domains	Potential probes
Knowledge and understanding	I have a lot of fear because I don't have enough information. I am concerned (worried) because the health care provider could not give me information.
Partner relationship	I am worried because my partner is not around. I worry about finances because my partner does not support me financially.
Interactions with the health care system (including access to care and quality of care)	I am concerned about paying for transportation, medication or childcare to attend clinic. I am concerned that I may need additional care or medication that I can't afford. I am worried that health care practitioners won't know how to help me.
Spirituality	I find relief from my worries when I pray or go to church. Believing in God helps me to feel peace when I am fearful.
Experience or fear of HIV/AIDS	I have a lot of fear because when I don't feel well as I think that I might be HIV positive. I have worries about my pregnancy because of my HIV status.

The literature on PRA[2-9] outlines the numerous adverse effects for both mother and baby; many of these consequences of PRA were echoed in the participants' narratives. Participants appreciated that "thinking too much" or worrying, was *bad* for them, as well as the baby. Partners/husband, friends, family, neighbours, and care providers informed these sentiments and "advised that the more you keep on thinking, the more you risk your baby" or you "might get miscarried or bear a child with weakness...don't stress, you might worry much and lose your life or the baby's." The stories of family, neighbours, and friends become increasingly valuable as a

source of information due to perceived lack of knowledge of health care professionals or lack of trust in their advice.

In LMIC such as Mwanza, the use of the word *support* was complicated by poverty, as often fathers/partners may continue to provide financial resources, exacerbating a woman's dependency for survival, while providing little to no practical or emotional support.[35] There is increasing evidence that mental health issues in women may be related to social circumstances, including poverty, violence, and economic dependence.[36] The stories of the women in this study are similar to previous studies that indicated the significance of financial supporting women's feelings of anxiety.[37]

Mwanza, and Tanzania in general, remains a highly patriarchal society in which women are often not given ownership of their decisions, including decisions regarding health and medical care.[35] Research colleagues in Mwanza indicated that this might be due to any number of issues, including inability to meet sexual needs, decrease in ability to provide for the home, or the partner's stress about providing for another child. For many participants, these gender-based realities of life influenced family roles, interactions, and emotional support mechanisms and evoked feelings of frustration, anxiety, hopelessness, and resignation. Lack of perceived control over a situation can affect an individual's uncertainty and insecurity, often leading to increased anxiety.[38] Nearly all of the women made reference to utilizing spiritual-positive coping—religion, prayer, or belief in a greater power or plan—to overcome distressing situations and their potential or actual negative consequences.[39, 40] Spiritual-positive coping offers a framework to help individuals make sense of the *bigger* life questions, placing the power of a situation on a

greater entity. This can have many effects, including a reduction of guilt and feelings of responsibility for a difficult or unfortunate situation.[41] Spirituality may lower anxiety levels, increase feelings of security, provide additional social support, and reduce worry.[42-44] Few studies have examined spirituality and mental health in Africa, despite it being recognized as a significant aspect of daily life in Tanzania.[44]

In LMIC, financial constraints, and multiple socio-political problems (e.g., poverty and economic instability) that burden health care systems.[45] contribute to worry and uncertainty throughout pregnancy. For participants with access to care the experience was at times disappointing due to negative events endured with health care providers. In Tanzania, antenatal services are widely available; however, quality of service and treatment remains an ongoing issue due to lack of trained personnel, inadequate supplies and equipment, and poor implementation of antenatal guidelines.[46, 47]

Three of the 10 participants were HIV-positive, yet HIV played a significant role in not only their stories, but in the lives of many of the participants. Many non-HIV positive participants expressed constant fear or anxiety about being diagnosed with HIV. Their worries did not indicate a positive diagnosis, but rather the reality of living in a highly affected area, with a heightened sense of the reality and risks of this illness. Women with HIV have higher anxiety symptoms during pregnancy due to maternal fears related to perinatal transmission of HIV.[48] All three of the participants with HIV openly discussed the intense fear of their child having HIV.

CONCLUSIONS

How social processes, poverty, and culture informs mental health of women during pregnancy remains unexplored.[2] The social, economic, and cultural realities of women residing in Mwanza were exemplified in themes of lack of knowledge, partner relationship, interactions with the health care system, spirituality, and fear of HIV/AIDS that emerged from the narratives of women experiencing PRA. Our study provides insight in this regard and adds new knowledge about the essence of PRA experienced by women in Mwanza, Tanzania. The PRA scale appropriately explicates participants' fear, worries, and concerns related to their own health and survival during pregnancy, their infants' health during pregnancy and survival, as well as caregiving ability in the postpartum. The PRA scale, however, narrowly reflects domains that inform our understanding of PRA of women in Mwanza, Tanzania and perhaps other LMIC.

Contributions: MKR and SSP developed the research question, designed the study, participated in data analysis and drafted the manuscript. ECN coordinated efforts in Mwanza, including translating documents, obtaining ethics approval, and coordinating local assistants. SRB and DE provided consultation from the research design through to the manuscript development. All authors have contributed to the work and approved the manuscript.

Funding: The University of Calgary Research Grant (URGC) Program, SEED Grant, funded the larger quantitative study. MRK's graduate studies was support by scholarships including Alberta Graduate Student Scholarship, Charlotte Firth Memorial Graduate Scholarship in Community Health Nursing, Education for the Future Master of Nursing Scholarship, and the Queen Elizabeth II Graduate Scholarship.

Acknowledgments: The authors are most grateful to the women who participated in this study and bravely told their stories. The collaboration and contributions of the Catholic University of Health and Allied Sciences in Mwanza are also acknowledged, as well as the research associates, assistants, and translators, particularly Dr. Ola Jahanpour and Miss Audrey Bernard. We thank Jill Norris for technical writing assistance.

Competing interests: None declared.

Ethics approval: University of Calgary Conjoint Health Research Ethics Board (REB13-0399: larger study; REB14-0660: this study; and REB14-0660-MOD-1: to include postpartum women) and the Catholic University of Health and Allied Sciences.

Data sharing statement: The authors are happy to provide additional information utilizing the contact information provided.

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APPENDIX

Interview Questions

1. Can you tell me about your experience so far in this pregnancy? Or Can you tell me about your experience while you were pregnant?

2. Tell me about a time during your pregnancy where you felt especially worried or concerned?

3. Tell me what worries you most about labour and delivery.

4. Tell me about a time when your worries were overwhelming or difficult to handle.

5. Tell me about how you would manage your worries at times when you felt especially worried.

6. What is the biggest concern you have about your pregnancy?

7. What is the biggest concern you have about the child?

8. What does it mean to you to have worries during your pregnancy?

9. Can you give me an example of a time where your worries affected your activities?

10. Can you give me an example of a time when you worries were relieved by a person or event? Or a time when your worries were not relieved?

11. Can you tell me what provided you with the most reassurance when you had concerns?

12. Can you tell me about any aspects of your relationship that have had an effect your worries?

13. Can you tell me about any aspects of your family or friends that have had an effect on your worries?

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	6
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	N/A
Occupation	3	What was their occupation at the time of the study?	Title page - aff
Gender	4	Was the researcher male or female?	N/A
Experience and training	5	What experience or training did the researcher have?	Acknowledge
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	3
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	6
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	6
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	5
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	6
Sample size	12	How many participants were in the study?	6
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	6
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	6
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	6
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	7
Field notes	20	Were field notes made during and/or after the inter view or focus group?	7
Duration	21	What was the duration of the inter views or focus group?	6
Data saturation	22	Was data saturation discussed?	6
Transcripts returned	23	Were transcripts returned to participants for comment and/or	8

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	7
Description of the coding tree	25	Did authors provide a description of the coding tree?	7
Derivation of themes	26	Were themes identified in advance or derived from the data?	7
Software	27	What software, if applicable, was used to manage the data?	N/A
Participant checking	28	Did participants provide feedback on the findings?	8
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	9-12
Data and findings consistent	30	Was there consistency between the data presented and the findings?	8-12
Clarity of major themes	31	Were major themes clearly presented in the findings?	Focus of paper
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	8-12

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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BMJ Open

A small qualitative study of pregnancy-related anxiety among women in Tanzania

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-016072.R1
Article Type:	Research
Date Submitted by the Author:	31-May-2017
Complete List of Authors:	Rosario, Melanie; University of Calgary, Faculty of Nursing Premji, Shahirose; University of Calgary, Faculty of Nursing; University of Calgary Cumming School of Medicine, Community Health Sciences Nyanza, Elias; Catholic University of Health and Allied Sciences, School of Public Health; University of Calgary Cumming School of Medicine, Community Health Sciences Raffin, Shelley; University of Calgary, Nursing Este, David; University of Calgary, Faculty of Social Work
Primary Subject Heading:	Global health
Secondary Subject Heading:	Mental health, Public health, Qualitative research
Keywords:	PERINATOLOGY, PRIMARY CARE, Anxiety disorders < PSYCHIATRY, PUBLIC HEALTH, QUALITATIVE RESEARCH

Title: A small qualitative study of pregnancy-related anxiety among women in Tanzania

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Keywords: Pregnancy-related anxiety; anxiety; women's health; pregnancy; global health

Word count: 5,005

ABSTRACT

Objectives: To explore and understand the experiences and priorities of pregnant women living with fears and worries related to fetal/infant and maternal health, the birthing process, and ability to parent the infant (i.e., pregnancy-related anxiety; PRA) in Mwanza, Tanzania.

Design: Descriptive phenomenological approach.

Setting: Two clinics in the Ilemela and Nyamagana districts of Mwanza.

Participants: Pregnant and postpartum women who obtained high scores on a PRA scale during pregnancy in a larger quantitative study were contacted to participate in an interview (10 women, aged 18-34 years; 3 HIV positive).

Measures: Semi-structured interviews were undertaken, with guiding questions related to the women's experience during pregnancy. The Colaizzi method was utilized with transcripts that had been translated and back translated from Swahili to English and then hand-coded by the interviewer, with independent review by another researcher to verify the analysis.

Results: PRA, as experienced by women in Mwanza, was a state of worry and concern, often causing physical symptoms, and disrupting personal sense of peace. While some themes in the women's experiences reflected the domains examined in the PRA scale used to identify potential participants, others such as lack of knowledge, partner relationship, interactions with the health care system, spirituality, and fear of HIV/AIDS were otherwise missing. Their prominence in the participants' stories broadens our understanding of PRA.

Conclusions: The realities and viewpoints of women in low- and middle-income countries (LMIC) experiencing PRA are still relatively unknown. The findings from this study provided much-needed insight into the perspectives and priorities of women in Mwanza who have experienced PRA and further support the need to explore this phenomenon in other LMIC. The

additional domains identified reinforce the need for a PRA tool that accurately and adequately capture the complexities of PRA for women in this region.

ARTICLE SUMMARY

Strengths and limitations of this study

- Partnerships with the local university in Mwanza allowed involvement and collaboration with local health professionals in the development of the method, recruitment, and data collection processes.
- Extensive international clinical and research experience by the researcher and supervisor was instrumental in creating relationships and opportunities for genuine interaction and conversation to ensure that the data collection and analysis process incorporated the voice of the women, local context, and culture.
- This is the first qualitative study of the experiences of women who have experienced PRA in Tanzania.
- The exclusion criterion was amended to include early postpartum women as many women from the associated quantitative study began to deliver before recruitment had been completed. While we acknowledge this alteration in the study design as a potentially significant limitation, postpartum women demonstrated the ability to draw from their experience during pregnancy and their stories were rich with detail.
- The stigma of mental illness and presence of a local third party (translator) may have affected the level of participation, engagement, or willingness of women to participate in the interviews.

- Due to time constraints, it was not feasible to return to the participants to present initial findings and collect feedback, as per Colaizzi's method.

INTRODUCTION

Pregnancy-related anxiety (PRA) has been strongly linked to preterm births, pregnancy complications, and negative infant outcomes in research from many high-income countries.[1-9] PRA is a syndrome that is distinct from depression, stress, or generalized anxiety.[10, 11] PRA encompasses several dimensions including fears and worries about the health and survival of the unborn child, having an 'abnormal' baby, the birthing process, developing medical problems during pregnancy, and ability to parent and care for the infant following birth.[10-16] In low- and middle-income countries (LMIC), the presence and impact of PRA will be even more pronounced given the high maternal and child mortality rates, poverty, and lack of resources.

In 2012, women in LMIC had a 1 in 150 risk of dying from complications in childbirth or pregnancy; this was in sharp contrast to a risk of 1 in 3800 for women in high-income countries.[17] In 2012, Canada reported 555 infants deaths due to complications from preterm birth, which is the greatest cause of neonatal deaths globally, whereas Tanzania reported over 17,000.[18]

Despite the potential harm of PRA in women from LMIC, their realities and viewpoints are relatively unknown, as qualitative studies to date have explored the broad phenomenon of antenatal mental distress in Ethiopia[19], and Malawi[20], rather than the more specific focus of PRA. Other qualitative studies such as a study from Ghana[21] have examined anxiety and fears situated in sociocultural beliefs, perceptions, and knowledge, which provide insight into the affective responses of pregnant women who are anxious.[11] The essence of PRA as experienced in the reality of pregnant women in LMIC is overshadowed by more widely recognized mental health concerns such as postpartum depression.

Attempts to transfer evidence from high-income countries to inform programs or initiative in LMIC, without alterations for cultural and contextual relevancy, have often proven to be unsuccessful, if not problematic.[22] In an effort to address the lack of knowledge about PRA in LMIC, this study explored the concept of PRA through the lived experience of pregnant women living in Mwanza, Tanzania. A Husserlian lens of phenomenology was integral in exploring the essence of PRA from the life-world of the participants rather than the imposition of the researcher [23]. Merging the researcher's perspectives with that of the participants' lived experienced, that is applying Heideggerian lens of phenomenology, was problematic and

counter-productive given the unique geographical, cultural, and contextual elements within the participant's experiences and environment [24, 25]. We present major themes in the participants' stories that did not reflect the domains of the PRA scale as it reflects the range of anxiety symptoms experienced by pregnant women in LMIC. We incorporate culture and context to understand the meaning given by the participants to the PRA experiences that have taken place.

METHODS

Women's experience of PRA was explored through the Husserlian lens of descriptive phenomenology[23-25] rather than a Heideggerian interpretive approach.[23] A reflective journal, commenced prior to starting the study and maintained throughout the study process, enabled the researcher (MKR) to recognize and set aside presuppositions, judgments, beliefs, experiences, and perceptions [26]. As such, bracketing permitted reducing the experience to the essence of PRA as experienced by women in Mwanza, free from conscious interpretation and researchers' influence.[23-25] Important elements of the participants' experiences—gender related inequities, low literacy, low education, and lack of decision-making authority—were clarified through field notes and peer debriefing.[25, 27] Peer debriefing, which occurred at the conclusion of each interview, enabled verification of local cultural nuances by 'cultural insiders' thereby minimizing personal or cultural bias [28]. To further enhance credibility, we acknowledged the community—employees and students at the Catholic University of Health and Allied Sciences office, local personnel (e.g., shopkeepers, taxi drivers, and neighbours)—as arbitrators of quality in discussing elements of local context and their meaning, as well as returning to raw data[28].

Setting and participants

The study sample was obtained from a quantitative study underway to examine the individual and collective contribution of PRA and depression in the prediction of preterm birth and postpartum depression.[29] The quantitative study recruited pregnant women from antenatal clinics in the Ilemela and Nyamagana districts of Mwanza, Tanzania. The clinic provided care to 40 to 50 women daily; 40% of these women deliver at hospitals and health centres that provide maternal and child health and delivery facilities.[29]

Purposive sampling was employed to identify women (a) 18 to 34 weeks' gestation, (b) able to speak English or Swahili, and (c) with high scores on the 10-item PRA scale,[14] which assesses fetal health, loss of fetus, childbirth, mother's wellbeing, parenting, and control/confidence.[11, 14] Eligible scores from the PRA with 4-point Likert scale were determined using Fairlier and colleagues'[30] recommendations of three or more responses indicating high anxiety. As research staff reviewed records of women enrolled in the quantitative study, they identified and contacted eligible participants. The potential pool of participants was smaller than anticipated, as contacting women after they had left the clinic proved challenging and women began to deliver. Through a consultative process with the research team of the quantitative study, and approved by ethics, the sample included pregnant and postpartum women with (1) high-anxiety with three or more responses indicating high anxiety, (2) two high anxiety and at least two moderate anxiety responses, or (3) one high anxiety and at least three moderate anxiety responses. Recruitment was ongoing as interviews took place; repetition of discovered information and confirmation of data that had been previously collected was achieved after 10 interviews, indicating data saturation.[31]

Data collection

A research associate inquired via direct telephone interaction, using a standard script in Swahili, about women's interest to participate in an interview in a private room at a familiar antenatal clinic. During the face-to-face contact, details about the study including purpose of study, time commitment, risks, benefits, privacy, consent, and voluntary nature of participation were shared prior to obtaining informed consent. A trained interviewer (MKR) conducted semi-structured interviews in the clinics in Mwanza from October to November of 2014. The interview guide (Appendix A) provided general questions to direct participants in a uniform manner; interviews were also participant directed and the interviewer took cues, probed, and requested further detail based on the information that was shared. Interviews were 40-75 minutes long, and were (a) conducted with the help of a Swahili translator, (b) audio-recorded with permission, (c) transcribed in Swahili, and (d) translated to English and back-translated to Swahili to ensure language equivalency. Field notes were maintained throughout the study and used to complement the interview data and emphasize the essence of the participants' experiences of PRA. Other sources of data included demographic information about the participants, which was obtained from the larger study to reduce participant burden.

Analysis

The Colaizzi method, with the exception of the final step of validating data with the participants, guided the analytic process.[31, 32] Each audio recording and transcript was reviewed numerous times while reflecting on field observations (e.g., facial expressions, gestures, disposition).[31]

Bracketing continued during this process to set aside beliefs, preconceptions, and values and be fully immersed in the participants' descriptions. Significant statements and phrases that pertained to PRA were identified, extracted, compiled into a separate document, reviewed, and associated with a formulated meaning and assigned to a broad category, or theme.[31, 32] A second researcher (SP) verified the process and ensured consistency in the meanings derived from statements, referring to the raw data as needed.[33] Formulated meanings associated with each significant statement were organized into categories or unique structure of clusters of themes and incorporated together to create a specific thematic impression.[31, 32] After merging all themes, we compiled a thematic map and an exhaustive description of the phenomenon of PRA in Mwanza, Tanzania.[31] Participant names were anonymized using pseudonyms and participant numbers correlating to the quantitative study.

We examined consistency of qualitative data against the 10-items on the PRA scale. Cross verification or triangulation of data enabled examination of the phenomenon of PRA from multiple perspectives.[34, 35] An additional method of triangulation, peer debriefing, prevented bias and allowed alternate points of view to emerge in the understanding of local context and culture.[27] Peer debriefing occurred with the interpreter, members of the community, employees and students at the Catholic University of Health and Allied Sciences office, and community members, including shop keepers, taxi drivers, and neighbours. Although the PRA scale reflected participants' experience, additional domains of PRA were also identified. The prominence of these domains in the participants' stories is important in broadening the understanding of the phenomenon of PRA. We present these additional domains of PRA in the findings.

Limitations

Enrolling women in postpartum period did not overly influence their ability to recall the experience of PRA as evident from the richness of the stories. Women were encouraged to reflect only on their experience during pregnancy. Noticeably, anxiety as a mental health concern was absent in women's narratives. Colleagues and research associates in Tanzania, rather than the participants' interview, related the social negative attitudes surrounding mental illness (e.g., work of evil spirits, possessed or bewitched). The stigma attributed to 'mental illness' and the presence of a translator may have affected the level of participation or engagement in the interviews.[36] The inability to return to the participants to validate the study findings is also acknowledged as a limitation.

RESULTS

All of the women resided in semi-urban areas, urban areas, or rural areas with reasonable access to semi-urban centers in Mwanza. Women were aged between 18 to 34 years of age. Of the 10 women, 4 were pregnant at the time of the interview and 6 had already delivered. Seven of the women (70%) were multiparous, and 2 had previously experienced the death of a child. Most of the women (90%) indicated that they were married or cohabitating with the child's father. Three of the women were HIV positive. Levels of education varied from no schooling to higher levels of basic education. Participants' characteristics are presented in Table 1.

Table 1. Characteristics of participants

Characteristics	**N=10**
Age	18 to 34 years

Marital Status	
• Single	1
• Married or Cohabitating	9
Parity	
• Primiparous	3
• Multiparous	7
Previous Loss of Child	
• No	8
• Yes	2
Pregnancy status at time of interview	
• Pregnant	4 (16 to 36 weeks' gestation)
• Delivered	6
HIV Status	
• Negative	7
• Positive	3

Five themes, presented in Table 2, did not reflect domains of the PRA scale: knowledge and understanding, partner relationships, interactions with the health care system, spirituality, and fear of HIV/AIDS.

Table 2. Additional domains of pregnancy-related anxiety as detailed by participant narratives in Mwanza

Additional domains	**Potential probes**
Knowledge and understanding	I have a lot of fear because I don't have enough information. I am concerned (worried) because the health care provider could not give me information.
Partner relationship	I am worried because my partner is not around. I worry about finances because my partner does not support me financially.
Interactions with the health care system (including access to care and quality of care)	I am concerned about paying for transportation, medication or childcare to attend clinic. I am concerned that I may need additional care or medication that I can't afford.

	I am worried that health care practitioners won't know how to help me.
Spirituality	I find relief from my worries when I pray or go to church. Believing in God helps me to feel peace when I am fearful.
Experience or fear of HIV/AIDS	I have a lot of fear because when I don't feel well as I think that I might be HIV positive. I have worries about my pregnancy because of my HIV status.

Knowledge and understanding

Lack of knowledge, or understanding of what was *normal*, was an underlying issue in many of the worries participants had about pregnancy and taking care of a new baby. Berta disclosed

> I get frantic at times because I know that my knowledge and understanding of what a baby might be suffering from in low. Currently she is active in my belly. But when she is born, she might cry at night and there is no one to help me learn what might be wrong with her. Mostly I will guess. But for the days and nights now, I worry what could happen to her because of me.

Margaret found herself asking people around her about symptoms she was experiencing. "For instance, last week I had very severe abdominal pain for about 3 hours; I could not sleep. People tell me that it is a normal situation." Neema experienced heightened anxiety as she could not understand her somatic symptoms explaining

> I felt bad and I was ill. About my health, after seeing myself very thin since I was so often ill, though it [was] for all my pregnancies but in this one it was severe with a lot of stress…The felling of body weakness and fatigability went throughout the pregnancy.

Both Neema and Margaret experienced symptoms that they feared might be attributed to HIV and were terrified that this might be the cause of their symptoms. Margaret "fail[ed] to eat" and

was "vomiting a lot," while Neema "felt ill", became "very thin," and was overcome with "weakness", all of which contributed to the fear of having HIV. Neema explained, "I was tested when I was about 8 months pregnant for HIV infection and I was fine, I was not infected. But all those months, I thought I was." Although both were tested and received results that they were not HIV positive, their lack of knowledge of common somatic symptoms of pregnancy caused significant distress.

Partner relationships

Grace described the support her partner provided after she and their first child was diagnosed with HIV as, "[he] didn't disturb or humiliate me as for why he has no AIDS and we do, he accepted us." Grace kept on thinking of the current pregnancy "if all my children will be infected how things would be. Even when I rest for a few days, about 3 or more days then the concerns keep on coming back." Neema candidly shared the worries caused as result of her husband:

> I don't know what was the issue but they say some might hate you when you are pregnant, I thought that was the reason. When you are in such situation and he comes asking for sex, it is an issue. It was very difficult for me…maybe because he found me often sick, maybe he was hurting inside…happiness diminishes, love fades away. I thought he might have been seeing another woman. I don't know, but at the late stages of my pregnancy be became close, he changed and that was a relief.

There were participants who had longed for emotional support from their partners but were unable to obtain it. Grace's husband travelled frequently; she explained "as his work is that he has to travel…he is often not at home…he does not stay at home most of the time. So it is not

easy to tell him what happens to me every day." Berta explained that at one point in her pregnancy,

> My partner took me to my parents' place and left me there. No one would talk to me without my husband there. Even visitors would only talk to my father. It was not like they were coming for me, or to know how I feel or how I was doing. They had no time to ask all that.

Conversations with research associates revealed that women in Tanzania (or Tanzanians in general) often do not discuss personal concerns with friends, or even family. Once Berta returned from her parents' place, she explained,

> During that time [pregnancy] my husband was not around, he had travelled. We had poor communication when he was away. Whenever I called, he was not reachable. At the time he was away, I was already confused because [of] my situation and I needed him… but at the time I couldn't get through to him, I was very worried during that time.

For participants in this study, the notion of *support* was contextually and culturally defined as financial support, as gleaned from peer debriefing. Aisha had moved to Mwanza from her rural hometown, where weeks passed since her partner left. Aisha had little contact with the father of her unborn child, and received little help when he did respond. "What gave me worries was…there were times I…asked for support and he wouldn't help me." Aisha had moved to Mwanza from her rural hometown, where weeks passed since her partner left. She recalled, "During that time, when it happens that I face financial issues and I ask him for help and he [father of the child] doesn't respond, I was just ... crying. What if I needed medicine?"

Interactions with the health care system

All participants in this study received antenatal care at least once during pregnancy. Margaret shared "I am used to calling the nurse whenever I get worse, I meet her and she helps me." Margaret would "do whatever the doctors instructed [her] to do" and found "I feel peace whenever I go to the hospital, since [she] gets advice from them to be well and keep [her] baby well." Joyce also recalled positive interactions with health care providers; however, "what I see is, they [health care providers] are more supportive in this pregnancy, especially the nurses. Whenever I face a problem they advise and help me." However, some women experienced less favourable interactions. Berta recalled a stressful week in which numerous providers contradicted her diagnosis of "low blood" (a common term used to mean anemia—often women will know this phrase in English without the need for translation) and informed her "that I might fall down or deliver a dead baby or that is how all of my reproduction will be." The worry in her voice and the expression on her face depicted even more than her words. Her voice grew shaky, her eyes began to water, and she fidgeted with her hands in her lap. Berta felt as though the interaction with health care providers had exacerbated her worries explaining:

> So she didn't give me clear information or encourage me. I felt like she was adding on my problems since when I was trying more to get information from her, she said 'There is this lady who came here with the same situation as yours'; I directed her, so let's find her, she can give reliable information. So herself as a nurse who was just advising me on my issue couldn't know where I could get help. So I feel she added on me a load in my thoughts.

Neema described a particularly difficult day in which she had arrived very early at clinic for assessing high blood pressure. Reflecting on the process of taking number to receive service she shared:

> I came early and I was ill on that day. I was the fourth lady to arrive. At a time we were provided with numbers I never knew, I had gone to the toilet and there were about 99 women in queue. I missed the number. The nurse refused to give me a number saying 'you were not around, there are people who were here early, you came late and you want number.' I shed tears, I was upset and sad, I felt bad and I was ill, I went into the room where they take physical measures.

Sarah had waited a long time to become pregnant thus when the time finally came, "I wished to see my stomach grows fast. I used to check up on myself every now and then I felt like my stomach was not growing, so I felt worried...if the child was alive inside my womb." Sarah described frustration in being advised to stay on bed rest after experiencing bleeding in the first trimester. She stated,

> I don't want to take the bed rest, though they advised me to, I figured out that I couldn't because I am working…I don't have much time to stay at home [considering that] I would have to take maternity leave after delivery. I was so worried, I was frustrated. That was very hard for me.

While routine prenatal care was provided free of charge in Mwanza,[29] strained relationships with health care providers, the inability to access additional services or lost time at work, was an underlying issue in many of the narratives.

Spirituality

The women's spirituality permeated many conversations, often woven among the fears and concerns they expressed. Imara had 3 girls and felt worried as her sister-in-law's wanted their brother to marry another women who may be able to give birth to boys. She explained how her belief in God helped her to "take heart" (i.e., took courage) by thinking:

> God is the one who provides, it is not like I am going to the market, that I choose I want this and that, no, I encouraged myself that God is the provider you can't say that I have only girls,…I believe God knows more and I don't.

Wema's "biggest worry was death" because "I was swollen all over the body, especially my feet and it was painful all over…the doctor I was advice, there were no any other cause except for the pregnancy." Wema's sister-in-law died from pre-eclampsia. When asked how she managed to cope with her worries, Wema simply replied, "I only prayed to God…I just pass through; it reach a point I had to take heart, thought it was God's plans." Similarly, Berta believed that "God is the one who knows it all..." including her own future and if she "will deliver safely or not." Despite her struggles, Berta "was encouraged by being thankful to God in everything." Sarah had experienced particular anxiety that her stomach was not growing large enough to indicate that a healthy child lay inside. For Sarah aside from her husband "Honestly, my other help was from prayers only. When I pray I get peace of mind. I stopped worrying. I believed my stomach would get larger. So as much as we talked and prayer, I felt peace."

Fear of HIV/AIDS

Fears of HIV/AIDS consumed the thoughts of the pregnant women who could not explain their somatic symptoms. Margaret explained that, "I was vomiting a lot, not eating well, it made me

have poor health and I became very thin. So I was thinking, I had not tested [for HIV] and I was very worried." She described feeling scared "after seeing myself very thin, though it [was] for all my pregnancies but in this one it was severe with a lot of stress." Neema, who also saw herself feeling thin and unwell, described,

> It was during my early pregnancy but the feeling of body weakness and fatigability went throughout the pregnancy, I was tested when I was about 8 months pregnant for HIV infection, I was fine, I was not infected. My worry was because I was often sick and had lost weight so much, so event that added in my thoughts.

The three HIV positive women had relatively recent diagnoses (within the past 3 years) were preoccupied with worries about their unborn child/infant, and concerns for their child's future if they were to pass away. Grace talked about her reactions to her HIV positive diagnoses:

> I was frightened and full of worries. I passed about three days without food since I had a lot of stress and thoughts, I was sad, I was worried and I cried so much. I never expected my baby be infected or even myself; I never knew until I became pregnant again and I found out that I was HIV infected together with my oldest child.

Grace also discussed her concerns about the antiretrovirals that she began taking during her pregnancy and their impact on her unborn child. She explained,

> Those drugs were bringing me different conditions [side effects]. I felt like dizziness and was thinking was these drugs to protect the child who was in my womb? If they make me feel this way, and in other days, I even lack sleep, with these conditions will my child be alive? Will the drug help me? I was worried.

Joyce's initial "concern was perhaps my child would also get infected, I asked the doctors, they reassured me and I stopped worrying." However, the initial reassurance faded as she considered her own diagnosis and then explained, "Both of my parents died and relative from my husband's side know nothing…I am worrying of delivering a baby who is HIV infected and was wondering what if I die early, who would I leave my baby with?"

DISCUSSION

The PRA Scale[14] has been identified as an appropriate tool for examining the experience of PRA for women in high-income countries.[11,16] Nonetheless, there have been claims that this tool, along with others designed to examine this phenomenon, displays relatively narrow domains that may not reflect the essence of PRA experienced by women.[37, 38] Our study confirmed this assertion for women in LMIC, specifically in Mwanza. Lack of knowledge, partner relationships, interactions with the health care system, spirituality, and fear of HIV/AIDS are suggested as additional domains based on their strong presence in the narratives and themes derived from the participants' stories. Table 1 provides suggestions for associated prompts related to each of these domains based on the participants' stories. Together with the PRA scale, these prompts may assist in developing a comprehensive measurement scale that will more accurately depict the sociocultural context of life in LMIC, specifically Mwanza, and therefore more accurately assess and identify pregnant women who are experiencing PRA in this region.

The literature on PRA[2-9] outlines the numerous adverse effects for both mother and baby; many of these consequences of PRA were echoed in the participants' narratives. Participants appreciated that "thinking too much" or worrying was *bad* for them, as well as the baby.

Partners/husband, friends, family, neighbours, and care providers informed these sentiments and "advised that the more you keep on thinking, the more you risk your baby" or you "might get miscarried or bear a child with weakness...don't stress, you might worry much and lose your life or the baby's." The stories of family, neighbours, and friends become increasingly valuable as a source of information due to perceived lack of knowledge of healthcare professionals or lack of trust in their advice.

In LMIC such as Mwanza, the use of the word *support* was complicated by poverty, as often fathers/partners may continue to provide financial resources, exacerbating a woman's dependency for survival, while providing little to no practical or emotional support.[39] There is increasing evidence that mental health issues in women may be related to social circumstances, including poverty, violence, and economic dependence.[40] The stories of the women in this study are similar to previous studies that indicated the significance of financial supporting women's feelings of anxiety.[41]

Mwanza, and Tanzania in general, remains a highly patriarchal society in which women are often not given ownership of their decisions, including decisions regarding health and medical care.[39] Research colleagues in Mwanza indicated that this might be due to any number of issues, including inability to meet sexual needs, decreased ability to provide for the home, or the partner's stress about providing for another child. For many participants, these gender-based realities of life influenced family roles, interactions, and emotional support mechanisms and evoked feelings of frustration, anxiety, hopelessness, and resignation. Lack of perceived control over a situation can effect an individual's uncertainty and insecurity, often leading to increased

anxiety.[42] Nearly all of the women used spiritual-positive coping— religion, prayer, or belief in a greater power or plan—to overcome distressing situations and their potential or actual negative consequences.[43, 44] Spiritual-positive coping offers a framework to help individuals make sense of the *bigger* life questions, placing the power of a situation on a greater entity. This can have many effects, including a reduction of guilt and feelings of responsibility for a difficult or unfortunate situation.[45] Spirituality may lower anxiety levels, increase feelings of security, provide additional social support, and reduce worry.[46-48] Few studies have examined spirituality and mental health in Africa, despite it being recognized as a significant aspect of daily life in Tanzania.[48]

In LMIC, financial constraints and multiple socio-political problems (e.g., poverty and economic instability) that burden health care systems[49] contribute to worry and uncertainty throughout pregnancy. For participants with access to care, the experience was at times disappointing due to negative events endured with health care providers. In Tanzania, antenatal services are widely available; however, quality of service and treatment remains an ongoing issue due to lack of trained personnel, inadequate supplies and equipment, and poor implementation of antenatal guidelines.[50, 51]

Three of the 10 participants were HIV-positive, yet HIV played a significant role in not only their stories, but in the lives of many of the participants. Many non-HIV positive participants expressed constant fear or anxiety about being diagnosed with HIV. Their worries did not indicate a positive diagnosis, but rather the reality of living in a highly affected area, with a heightened sense of the reality and risks of this illness. Women with HIV have higher anxiety

symptoms during pregnancy due to maternal fears related to perinatal transmission of HIV.[52] All three of the participants with HIV openly discussed the intense fear of their child having HIV.

CONCLUSIONS

How social processes, poverty, and culture informs mental health of women during pregnancy remains unexplored.[2] The social, economic, and cultural realities of women residing in Mwanza were exemplified in themes of lack of knowledge, partner relationship, interactions with the health care system, spirituality, and fear of HIV/AIDS that emerged from the narratives of women experiencing PRA. Our study provides insight in this regard and adds new knowledge about the essence of PRA experienced by women in Mwanza, Tanzania. The PRA scale appropriately explicates participants' fear, worries, and concerns related to their own health and survival during pregnancy, their infants' health during pregnancy and survival, as well as caregiving ability in the postpartum. The PRA scale, however, narrowly reflects domains that inform our understanding of PRA of women in Mwanza, Tanzania and perhaps other LMIC.

Contributions: MKR and SSP developed the research question, designed the study, participated in data analysis and drafted the manuscript. ECN coordinated efforts in Mwanza, including translating documents, obtaining ethics approval, and coordinating local assistants. SRB and DE provided consultation from the research design through to the manuscript development. All authors have contributed to the work and approved the manuscript.

Funding: The University of Calgary Research Grant (URGC) Program, SEED Grant, funded the larger quantitative study. MRK's graduate studies was support by scholarships including Alberta

Graduate Student Scholarship, Charlotte Firth Memorial Graduate Scholarship in Community Health Nursing, Education for the Future Master of Nursing Scholarship, and the Queen Elizabeth II Graduate Scholarship.

Acknowledgments: The authors are most grateful to the women who participated in this study and bravely told their stories. The collaboration and contributions of the Catholic University of Health and Allied Sciences in Mwanza are also acknowledged, as well as the research associates, assistants, and translators, particularly Dr. Ola Jahanpour and Miss Audrey Bernard. We thank Jill Norris for technical writing assistance.

Competing interests: None declared.

Ethics approval: University of Calgary Conjoint Health Research Ethics Board (REB13-0399: larger study; REB14-0660: this study; and REB14-0660-MOD-1: to include postpartum women) and the Catholic University of Health and Allied Sciences.

Data sharing statement: There are ethical restrictions that prohibit us from making data publicly available. We do not have permission from the participants to share all the interview data stemming from this study, especially the transcripts from the interviews. During the informed consent process, we indicated that the data would be shared in aggregate.

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APPENDIX

Interview Questions

1. Can you tell me about your experience so far in this pregnancy? Or Can you tell me about your experience while you were pregnant?

2. Tell me about a time during your pregnancy where you felt especially worried or concerned?

3. Tell me what worries you most about labour and delivery.

4. Tell me about a time when your worries were overwhelming or difficult to handle.

5. Tell me about how you would manage your worries at times when you felt especially worried.

6. What is the biggest concern you have about your pregnancy?

7. What is the biggest concern you have about the child?

8. What does it mean to you to have worries during your pregnancy?

9. Can you give me an example of a time where your worries affected your activities?

10. Can you give me an example of a time when you worries were relieved by a person or event? Or a time when your worries were not relieved?

11. Can you tell me what provided you with the most reassurance when you had concerns?

12. Can you tell me about any aspects of your relationship that have had an effect your worries?

13. Can you tell me about any aspects of your family or friends that have had an effect on your worries?

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	6
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	N/A
Occupation	3	What was their occupation at the time of the study?	Title page - aff
Gender	4	Was the researcher male or female?	N/A
Experience and training	5	What experience or training did the researcher have?	Acknowledge
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	3
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	6
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	6
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	5
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	6
Sample size	12	How many participants were in the study?	6
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	6
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	6
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	6
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	7
Field notes	20	Were field notes made during and/or after the inter view or focus group?	7
Duration	21	What was the duration of the inter views or focus group?	6
Data saturation	22	Was data saturation discussed?	6
Transcripts returned	23	Were transcripts returned to participants for comment and/or	8

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	7
Description of the coding tree	25	Did authors provide a description of the coding tree?	7
Derivation of themes	26	Were themes identified in advance or derived from the data?	7
Software	27	What software, if applicable, was used to manage the data?	N/A
Participant checking	28	Did participants provide feedback on the findings?	8
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	9-12
Data and findings consistent	30	Was there consistency between the data presented and the findings?	8-12
Clarity of major themes	31	Were major themes clearly presented in the findings?	Focus of paper
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	8-12

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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