

Doing qualitative research on dementia with family caregivers in Kenya: A reflection on fieldwork experiences

Purity Mwendwa¹

Abstract. In this paper, I present reflections on a self-funded study that explored the experiences of caring for people with dementia (PWD) in Kenya. I use an autoethnographic approach to examine and discuss some key issues that emerged during the planning and fieldwork phases of the study. This approach entails auto-reflection and the analysis of each part of the research experience. This paper does not report on the study's findings but provides an understanding of the difficulties encountered while researching in Kenya on a topic which is little understood. The paper begins with a background to the study, followed by the motivation of conducting the research. I then discuss the critical issues encountered during the various phases of the project. These included i) difficulties securing funding for the project, ii) challenges recruiting participants and iii) the lack of emotional support for the researcher during this process. The paper also offers suggestions on strategies that could benefit researchers seeking to study a similar problem in this context.

Keywords: *dementia, caregiver, qualitative fieldwork, autoethnography, sub-Saharan Africa, Kenya*

Background

Family caregivers play an essential role in caring for people with chronic conditions, such as dementia, who often have complex care needs (Brodaty & Donkin, 2009). In sub-Saharan Africa (SSA) caregivers are most of the time the only support available to older family members. This is based on the cultural configuration of society, as well as a result of limited government support for older people (Aboderin & Hoffman, 2015). Dementia includes a group of symptoms that affect the memory and the ability to carry out basic daily tasks such as bathing, dressing or even feeding (World Health Organisation, 2019). Dementia results from different diseases that affect the brain with Alzheimer's disease considered the most common cause (The Alzheimer's Association, 2020). Current global estimates suggest that

¹ UCD Centre for Interdisciplinary Research Education and Innovation in Health Systems (UCD IRIS Centre), School of Nursing Midwifery and Health Systems, University College Dublin.
(purity.mwendwa@ucd.ie)

there are 50 million people with dementia (PWD) (World Health Organisation, 2019), and in 2015, 2.13 million people were living with dementia in SSA. With the numbers of PWD expected to rise to 3.48 million by 2030 (Guerchet et al., 2017), the care needs of this population are expected to increase (O'Shea, 2007).

Dementia is not well known or recognised in most SSA countries (Mushi et al., 2014). In this context, dementia is often believed to be a normal part of ageing, and most families support the PWD at home (ibid.). A lack of diagnosis or misdiagnosis (Bradford et al., 2009), stigma (Faure-Delage et al., 2012), social isolation for PWD and their caregivers (Schoenmakers, Buntinx, & Delepeleire, 2010), and lack of national dementia policies (Heslop & Gorman, 2002) are some of the factors that make dementia care challenging. And while research on family caregivers is growing in the region, little is known about the impact of caring for a PWD (Mwendwa & Kroll, 2019). Available research has focused on the experiences of those caring for younger populations, for example, children with a (physical) disability (Geere et al., 2013), caregivers for children and people with HIV/AIDS (Abasiubong et al., 2011). Such a gap in evidence limits the ability to highlight the critical role played by caregivers for PWD and has implications for their consideration in national and local health policies and budgets.

Research, mainly qualitative, is suited to exploring the impact that dementia places on PWD, caregivers and families (Prorok, Horgan, & Seitz, 2013). However, designing and implementing such research presents several obstacles including: inadequate funding for research projects; difficulties recruiting participants for studies; ethical dilemmas (Carmody, Traynor, & Marchetti, 2014), researchers' lack of understanding and knowledge of the socio-cultural context (Hinton et al., 2000) and little or no emotional support for researchers while in the field (Mitchell & Irvine, 2008). In a context where little research on caregivers for PWD is available, it becomes imperative to understand potential difficulties associated with conducting such research and strategies that may serve to overcome them. Such information can benefit researchers seeking to include caregivers for PWD in their research projects.

This paper shall proceed as a first-hand account of the fieldwork as experienced by the author. This narration is purposely done in the first person, to enable the reader to join the researcher (author) and the routes taken in completing this research study.

The rest of this article describes my personal experiences in planning and implementing a research project that explored the experiences of caring for a PWD in Kenya. The purpose of this article is to (a) highlight the challenges to planning and implementing the project, (b) identify the strategies that were employed to overcome the difficulties and (c) provide recommendations to future researchers. I use autoethnography, an approach to research and writing, that aims to describe and systematically analyse (*graphy*) personal experience (*auto*) and provide an understanding of cultural experience (*ethno*) (Ellis, Adams, & Bochner, 2010). Anderson (2006), distinguishes two types of autoethnography; evocative and analytic autoethnography (AA). I employed the former, as it required mainly the description of the researcher's own experiences and feelings as opposed to the AA whose main aim is the analysis of data and comparison of the outcomes with other empirical data (Anderson, 2006).

Motivations for undertaking the project

This project was driven by my personal experience with dementia (having a parent with dementia) and experiences of caring for PWD (being a professional caregiver). These personal factors, coupled with being a seasoned researcher in social sciences, were hugely beneficial in informing the design and implementation of this project. Before embarking on the project, I felt that, being relatively new to researching the topic, my understanding of the topic and potential impact of the project would be limited without grasping the foundational concepts related to dementia. With this in mind I took to self-directed learning (Knowles, 1975) and completed various e-learning modules including 'Understanding dementia' and 'Preventing dementia,' both offered by the Wicking Dementia and Research Centre at the University of Tasmania, Australia.

To enrich my knowledge on dementia, I continue to attend conferences, seminars and workshops on the topic and read books written by PWD and by caregivers of PWD. I have recently completed an online *family carer training* that is offered by the Alzheimer's society in Ireland. This experience has expanded my knowledge and understanding of dementia care and strengthened my competence and confidence about speaking on the topic. I have also, held several outreach events in Kenya to raise awareness about dementia.

Funding the project

I will borrow from Zoe Muller's blog post (Muller, 2017) in which she writes about the pros and cons of self-funding for academic research and says "If you want something badly enough, you make arrangements. If you don't want it badly enough, you make excuses." I made no excuses, and that is why, after several unsuccessful funding applications, I decided to self-fund the project. At this stage in my career, I have become accustomed to writing proposals for funding, been successful at a few, and disappointed at most. Recent evidence suggests that the success rate for proposals in Europe is quite low, around 12.6 % in 2019 (Nature, 2019). While I am still honing my grant writing skills with every proposal that I draft, I would argue that my biggest hurdle to success at securing funding was being a "newbie" on the topic. Albeit armed with a ton of transferable skills, having little knowledge and experience on this topic was probably one reason funders did not see the potential for the work I was proposing to do. In hindsight, I realised that I was not applying to the right funders, but that equally, I may have failed to effectively communicate to funders and convince them that while being a "newbie" I was worth funding (Nature, 2019). One of the ways I could have increased my chances of securing funding was to collaborate with colleagues who have particular expertise on the topic (Sternberg, 2014). Yet, this experience enhanced a whole range of skills, not least, honing my grant-writing and communication skills, time and financial management, and I should mention patience! (as I waited for that crucial decision email from funders).

Pre-fieldwork phase

Ethical approval and research permit

In Kenya, ethical approval is provided by accredited ethics review committees listed on the National Commission for Science, Technology and Innovation (NACOSTI) website (NACOSTI, 2020). For this study, I obtained ethical approval from two ethics review committees: Kenya Methodist University (KEMU) and from my institution, University College Dublin in Ireland. Subsequently, I obtained a research permit from NACOSTI. Prior to the study appropriate authorities in the counties where the study was to be conducted were informed of the study and provided approval. Care was taken in explaining what the study entailed and any potential risks and information sheets for participants, including consent forms, were translated into the local languages (Ramsay et al., 2014). Informed consent was obtained from each participant. However, ethics in this context is more than just explaining what the study is about and signing forms; it mandates being tuned into the cultural environment and understanding the cultural expectations (Gokah, 2006). Familiarity with the context and experience researching in this context meant that I was well aware of the expectations of me as a researcher.

Sampling techniques

I used convenience sampling (Etikan, Musa, & Alkassim, 2016) to select the study sites and used my existing relationships with organisations in these sites to identify families with a PWD. Before the study, I invested considerable time (at least six months) liaising with caregiver support groups and organisations working with older people to promote the project and identify potential participants. I also gave talks in churches and met with community groups within the selected study sites to talk about the proposed project and gauge the feasibility of conducting the study.

Overall, my familiarity with the context worked to my advantage. For example, apart from being familiar with the social-cultural aspects of the context, I was also well versed with the processes of acquiring ethical approval and research permits, based on my past experience with previous submissions. Others may argue that familiarity can sometimes jeopardise the research process, particularly when the researcher, who by all counts believes that he or she 'belongs', is suddenly treated with suspicion, deemed an 'outsider' and 'intruder' in his or her own native country (Gokah, 2006). When I showed up late to one of the interviews, one of the participant's said: "... when I was told you now live in Europe, I said I better not keep to the African time. When I arrived and you were not here, I thought to myself, what? I am here before the mzungu²?" In my experience having lived or studied abroad makes locals at times treat researchers differently, viewing native-born researchers as foreign, an experience shared by others (ibid.).

² of European descent

Participant recruitment

Recruitment is often a challenging aspect of research but one which is not adequately addressed in the current literature (Riedel-Heller, Busse, & Angermeyer, 2000). Identifying and recruiting caregivers for PWD, particularly in rural locations where dementia is not well understood, was a challenge for this study. Previous research has cited logistical and practical difficulties such as distance to travel sites (Morgan et al., 2019), opportunity costs, and language (Shanley et al., 2013) as barriers to participation in dementia-related research. Social and cultural differences related to dementia between populations may influence the success rates of recruitment (Kwon & Kim, 2011). Having a family member with dementia symptoms carries a social stigma in this context, which may have led families to shun participation.

The importance of building trust with gatekeepers to help identify potential participants cannot be overstated. I identified gatekeepers through personal contacts and people working closely with communities, particularly with older adults. One of the key lessons from this was the need to establish a good and close working relationship with the gatekeepers, over a considerable time, at least 6 months to one year, before the study (although current funding structures don't always allow for this). This helps to build their trust and support for the project. The gatekeepers were instrumental in advising me about the most effective strategies to help recruit participants.

Personalised communication with potential participants, including face-to-face contact, has been noted as a successful recruitment approach in other studies (Riedel-Heller et al., 2000). Discussions with potential participants need to demonstrate why the study is important and potentially beneficial to the individuals. It is notable, that participants in this context may have difficulties understanding academic research and its potential to help address the problems they face on a day to day basis. Equally, time emerges from the literature as a key aspect of the recruitment strategy that requires incorporation into research costs (Bartlett, Milne, & Croucher, 2018). Arranging visits at a time that is convenient for the potential participant (Mody et al., 2008), and providing enough time to enable discussion about the study (Norton et al., 1994) are important to encourage and enable participation.

The interview

Despite the difficulties encountered, we managed to recruit and interview 10 family caregivers from three counties in the country. The interviews took place in the home environment with the PWD present or at a location that was convenient for the caregiver. Interviews were conducted, at the request of the caregiver, in either English, Swahili or Kimeru.

As alluded to prior, most caregivers did not quite understand the purpose of interviews, and the potential benefits of the information they were to provide. Previous research with ethnically diverse communities shows that research may be new and confusing to participants (Shanley et al., 2013). For most, this was the first research interview and hence every effort was made to provide a detailed explanation of the study and the potential impact in the local

language (tailored to the caregiver's needs). I believe having first-hand understanding and knowledge of the socio-cultural context, being conversant in two local languages (Swahili and Kimeru) and having conducted various interviews with communities in this context made this process much easier.

In five of the ten interviews conducted, the PWD was present at the interview as these were conducted in the home environment. I observed that time and again as the interview with the caregiver progressed the person with dementia would make gestures, smile, laugh or utter something that was evidently in response to the interview. As the interviewer, it felt odd, sitting there and talking about the PWD as though they were not present. As I listened to the interview recordings and reflected on the experience of doing this work, I was reminded of a quote from Kate Swaffer's book: "What the hell happened to my brain?" in which she writes "...people with dementia are still not included in the really important conversations about them, and we are still such a long way from being dementia-friendly"(Swaffer, 2016, p.66). There is no straightforward and easy way of interviewing caregivers at home and excluding the PWD; in all instances where the PWD was present the caregiver was the only person in the home at the time.

Another important issue I observed during the interviews was how most caregivers seemed at ease and spoke openly, providing vivid descriptions about their journey. I was struck by how some recalled details for example relating to dates (year) when the PWD began developing symptoms, the number of times they had been to see a health care professional seeking help or a diagnosis, the type of tests performed, including the names of medications prescribed at the initial stages to manage the condition. I believe having shared my own experience at the beginning of the interview may have served to "..... minimise the distance and separateness of researcher-participant relationships" (Karnieli-Miller, Strier, & Pessach, 2009, p.279). Closely linked to this, I would argue, is how the interviews were conducted. Indeed, on listening to the recordings, I now realise how much time I allowed the participants to speak at a comfortable pace without interruption, paraphrasing and reflecting on their emotional story (Guion, Diehl, & McDonald, 2011). Having conducted several research interviews over the years no doubt has improved my ability to be an active listener. Potentially useful advice for new researchers in this context, is to allow adequate time on the interview date for introductions and sometimes prayers. In some cases, the host will offer tea to the guest before or after the interview. It would be regarded disrespectful to disregard such hospitality.

Caregivers were compensated for their time and reimbursed for their travel expenses, where applicable. In accordance with sound ethical practice in Africa (Njue et al., 2015) participants received cash as opposed to non-cash benefits as this would allow them to prioritise their own needs. The actual amount paid to participants is important and affects whether it is considered undue influence or whether this is justifiable (Alzheimer Europe, 2011). In my experience reimbursement should be based on the number of hours they commit to the study and their travel costs and respite care allowance factored in.

After the interview

I now acknowledge that this research experience was emotionally draining and at times distressing. Often, I was overcome by what I saw in the homes I visited to conduct interviews, particularly how the caregiver was struggling to manage the care for the PWD and on other occasions, by the stories they shared with me. In several interviews, caregivers got very emotional and fortunately, there was support available to them. However, for me, there was no specific local emotional support system built into the study and other studies have reported this (Mitchell & Irvine, 2008). I truly had not anticipated the emotional effect this process would have on me. What I found helpful, at times, was discussing my field experiences over the phone with a colleague who was also part of the study, but not based in the field, to provide an update about how the fieldwork was progressing. Future work on this topic must consider the potential emotional impact for researchers and ensure that local support is built into the study.

Conclusion

My personal experiences with dementia provided a motivation for this study. Using autoethnography, this paper offers a reflexive account of my fieldwork experiences as a seasoned researcher, researching a new and what is regarded as a stigmatised topic in this context. This article has discussed a range of challenges related to designing and conducting research with caregivers for PWD in Kenya. A key challenge for the research process was recruitment. I argue that the labels people use to describe dementia and the attributions they make to its causes made recruitment much harder. Based on my experiences with this project, I maintain that successful recruitment and retention of participants is contingent on identifying key stakeholders in the communities and holding face-to-face meetings prior to the study. Coupled with the fact that dementia is not well understood in this context, it is essential for future research to explore the meanings attached to dementia among the different ethnic groups (Cipriani & Borin, 2014). This information has the potential to inform the design of support and services for PWD and their caregivers and can also contribute to public health messaging.

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