

*'When you are a data collector you must expect anything'. Barriers, Boundaries and Breakthroughs: Insights from the South African data collection experience.*

## **Abstract**

The impact of the research process on the researcher is an emerging topic of interest. Data collection in most low and middle income countries (LMIC) is often the responsibility of community members who are identified and trained specifically for data collection. When research involves data on mental health and social wellbeing, data collectors may have specific competency needs and the task of data gathering may impact data collectors. This study aims to explore the experiences and needs of data collectors within South Africa using qualitative methods to examine the impact of data collection on data collectors. Nineteen data collectors, involved in face-to-face data collection, completed semi-structured interviews exploring insights, attitudes and experiences. Thematic analysis revealed barriers and challenges associated with research, complexities regarding boundaries within the participant-data collector relationship and the benefits of being involved with research for the individual and the community. Numerous challenges and opportunities are outlined. Findings expose the beneficial and often overlooked contribution of data collectors and warrants key considerations in the planning and implementation of future research to ensure adequate support and standardisation of practice.

## **Introduction**

Data collection is the foundation of research, and while the impact of conducting research on participants has been extensively documented(1,2), only recently has literature emerged regarding the effects of undertaking research on the researcher. Physical as well as emotional risks to the wellbeing of researchers have been identified. These risks include disease and injury(3,4), as well as psychological strain(3-7) and role conflict; the expectation to fulfil the requirements of incompatible status roles (i.e.role of researcher and community member), often caused by quasi-therapeutic relationships with participants(3,4). Yet, most studies are restricted to the experience of principal investigators. Only few studies have highlighted the experience of data collectors and those involved in participatory research(8,10). Within LMIC, the use of data collectors is increasingly common. Expertise in LMIC is often limited, resulting in a constrained capacity to undertake research(11,12), as

such, local community members are often upskilled to undertake data collection(13). Data collectors are essential to community-based research. Yet, they are also often detached from the larger research team(14), as such their experience and engagement with the research process may fundamentally differ from senior researchers. Research detailing the experiences of data collectors is critical to inform practice.

Participatory research involving members of the local community is often seen as a mechanism for empowerment for both individuals and communities(9). Individuals have reported a growth in skills, and confidence from being involved in research, reporting indirect benefits for the community including social action and advocacy(9,10). Additionally, the involvement of such individuals has been found to have benefits for the facilitation of research, as community members are seen to be culturally and linguistically more appropriate(9,15-17). Sharing a similar background to participants may allow for data collectors to build trusting relationships and navigate access to potentially hard to reach participants, this in turn may have implications for data quality and data utility(18).

There are practical, emotional and ethical risks faced by data collectors. In LMIC, data collectors often work within contexts of poverty, health inequality and violence. They are frequently based within communities, meeting at participant homes(19,20) or within geographically isolated areas(11,21-23), making personal safety an issue. Those working with sensitive data may experience distress associated with the emotional demands of their role(8,19,24). Within such contexts, data collectors have reported feeling a moral obligation to assist participants in need(25-27), often beyond their role. Associations with the community(28), may result in the emotional risks associated with data collection being compounded(9). As such, emotional proximity and the potential for role conflict bring about considerations regarding the objectivity of data and possible ethical considerations regarding professionalism and confidentiality(9,21,28,29). Such issues necessitate specialised skills, for which some may feel ill-prepared if there is no appropriate training or infrastructure.

Much of the literature explores the implications of undertaking qualitative research for the researcher. However, little attention has been given the implications of undertaking quantitative

research. Within LMIC, for practical and logistical reasons, quantitative data collection (questionnaires) often takes the form of interviews. Therefore, these data collectors may share similar experiences to those collecting qualitative data. While certain types of data collection, e.g. height, may not have an emotional impact, more probing questionnaire data within the social sciences exploring topics such as mental health, social wellbeing or trauma can be emotive.(30) Understanding the impact of data collection is vital to ensuring the wellbeing of this group, the veracity of the data and the integrity of the research process. This study aims to explore the experiences of data collectors working within community-based settings in South Africa.

Drawing on the above, previous literature focused on community-based research and notions of participatory research; scientific objectivity, empowerment and social action(9,31-33), frame the interest in the experience of data collectors within this study. Being a data collector within LMIC is a unique role that is essential for the research process, data integrity and any subsequent repercussions of research findings. A lack of research in this area is problematic as higher-level researchers may not be aware of the context or potential challenges of data collection for this group. It is important to understand the experience of data collectors to ensure that any support or training needs are adequately addressed, to understand the impact on research and data quality, and to inform future practice(9,17).

## **Methods**

This exploratory study is nested within a wider project within South Africa with both quantitative and qualitative components. In this study, semi-structured interviews with 19/125 data collectors involved in the wider project were undertaken and transcripts were analysed using thematic analysis.

Ethical approval was granted by Stellenbosch University(HS1172/2015). Written informed consent was obtained from all participants, with the understanding that data would remain anonymised. Limited demographic information has been used in the presentation of data to protect participant identity.

## **Sample**

A list of 36 prominent researchers in South Africa was identified by the principal investigators of the larger project. These researchers were contacted and asked if they worked with trained community data collectors who could be invited to contribute to the wider project. They identified 125 collectors from four provinces within South Africa (Western Cape; Eastern Cape, Gauteng, KwaZulu-Natal), with a history of employment in face-to-face data collection. Those participants who gave consent were contacted to provide information regarding the wider study and screen for eligibility. The inclusion criteria for the wider project required participants to have experience of community-based data collection in the previous 12-months and be above age 18 years.

Opportunity sampling from the 125 participants in the wider study was used until qualitative analysis reached saturation. In total, 19 participants, from the Western and Eastern Cape provinces, were invited to complete semi-structured interviews. No participants refused to participate.

## **Data collection**

Participants were given a choice as to whether interviews were conducted in English or Xhosa, all participants chose Xhosa. Interviews were conducted by trained data collectors in neutral locations e.g. community centres. Interviews were audio-recorded to ensure validity and reliability of the data (34), and were transcribed and translated to English for analysis. Randomly selected transcripts were checked for accuracy (both content and translation) by an independent bilingual researcher to ensure reliability. An interview schedule of open-ended questions developed to explore personal understanding and experiences of data collection was used to guide the interviews and to ensure consistency and coverage across interviews. The schedule was used to provoke discussion regarding the data collection experience, attitudes and wider impacts. The schedule was drawn from topics within previous literature focusing on data collectors and principal investigators, i.e. challenges and difficulties associated with data collection, positive experiences, and perceptions of the role of the data collector. An independent bilingual researcher checked the fidelity of interviews to the topic guide to assess quality of protocol implementation. Interviews lasted between 1-2 hours (mean duration=1:23:44).

Interviews were conducted by experienced, Xhosa speaking fieldworkers who had extensive experience of data collection. All fieldworkers were female and had worked in similar environments to participants. Fieldworkers were unknown to participants but having had shared experiences, may have had similar world views. This shared background was considered to have a positive impact on the data collection process as participants were forthcoming with their experiences. It was also seen as more appropriate than senior researchers conducting the interviews, with reference to the power dynamic within interviews.

### **Data analysis**

All interviews were coded and analysed by trained qualitative researchers using a thematic approach(35). Themes were developed based on concepts of perceived challenges and positive experiences from the literature(3-7,9) and were informed by concepts of empowerment and issues regarding scientific neutrality drawn from the field of participatory research.(31-33) Themes were identified at a semantic level and were closely linked to the data.(35) ATLAS.Ti(36) was used to aid data management. Transcripts were subjected to a line-by-line examination and manually coded using an iterative process to inform wider themes. Initial codes for each manuscript were developed by two researchers independently and compared. A team composed of seven members, inclusive of principal investigators, met to interrogate and elaborate on themes and higher-order themes. Differences were resolved through discussion. Themes represent repeated patterns of meaning across the data(35). Themes were reviewed for consistency, through the examination of all coded extracts, and whether themes accurately mirrored the meanings evident within the dataset(35). The relationship between themes was examined using conceptual maps. Final key themes, made up of amalgamated clusters of similar themes, were selected based on prevalence, richness and the importance placed upon them by participants. Following formulation, themes were subjected to respondent validation by two participants. Themes are supported in the write-up with illustrative extract examples. Results are indexed using participant age and location (WC;Western Cape, EC;Eastern Cape).

Data analyses were undertaken by researchers at differing stages within their career with experience of both quantitative and qualitative research. All had prior experience of working within LMIC with data collectors.

## Results

Qualitative data were collected from 19 participants (100% female) with a mean age of 41.8 years (SD=10.72; Range 25-65 years). The sample originated from South Africa and the majority 94.7% (18/19) described themselves as Black African. Xhosa was identified as the prominent primary language (89.5%; 17/19), followed by English (10.5%; 2/19). Almost 70% reported living in formal housing structures as opposed to settlements or informal dwellings. Data collection was a full-time occupation for 42.1% (8/19) of the sample. Almost all had experience of working on two or more research projects. All had undertaken training, the majority (94.7%; 18/19) receiving training for one month or less.

### **Themes**

Focusing on the challenges and impact of data collection on data collectors within community settings, nine themes emerged from the data. These first-order themes were subjected to higher-order analysis from which three global themes arose: **barriers**, **boundaries** and **breakthroughs**. **Barriers** refers to the difficulties and challenges that data collectors encountered that may have infringed on the data collection process. **Boundaries** highlights the data collector-participant relationship and the somewhat antagonistic role of data collectors as impartial researchers and members of the community. Lastly, **Breakthroughs** refers to the progressive impact of the research process upon individuals and the wider-community.

### **Barriers**

Respondents reported that they found their role challenging based on logistical, physical and emotional hurdles. The resultant three themes which emerged related to a lack of *safety*, *problems accessing the community*, and a *lack of wellbeing*.

### **Lack of safety**

Data collectors stated that they felt unsafe while working, which was often found to hinder the research process. Many reported feeling unsafe within specific geographical locations stating they had experienced dangerous situations and violence. Being a target for violence while working as a data collector was a concern for some: *'People are robbed and they are raped as well....researchers are targets for thugs'***36,WC.**

Practical issues within particular contexts, such as a lack of transport or difficult terrain, left many data collectors feeling fearful of their working environment. As such, many would not work alone because of potential risks. The practicalities of ensuring safety were framed as a fundamental challenge in the data collector role.

### **Problems accessing the community**

For some, accessing communities to undertake data collection posed a significant challenge and was a hindrance to timely project completion. Permissions from chiefs or street committees are often required within LMIC and this was often reported as leading to delays during data collection.

*'We experienced that we would not start because we were waiting for the street committee.... We would have a problem with time.'***57,WC.**

### **Lack of wellbeing**

High and variable workloads were commonly reported as a barrier for data collectors. Many highlighted the physical and emotional challenges arising from their work. Some found the work to be tiring and emotionally taxing. Many commented on how they often thought about their role outside of work, finding the demands and deadlines somewhat stressful.

*"... sometimes I just feel tired and drained especially if I had to do more than the other person."***38,WC**

*"I would be sitting at home and feel that the work is stressful"***57,WC**

Despite such challenges, many described effective coping mechanisms inclusive of religious beliefs, relationships and supervision with higher-level researchers. Debriefing with other data collectors on the project, regarding difficult experiences with participants, was found to be helpful:

*'Normally [we] have meetings, it's where a person share[s] an experience that was tough and with team it helped. Like after work we stay and share the way you felt...'***38,WC.**

## **Boundaries**

Most commented on the development of empathetic relationships with the participant. The notion of 'boundaries' as a global theme illustrates the complexities that emerge within the data collector-participant relationship. It focuses on the distance between data collector and participant, highlighting challenges associated with striking a balance between being an impartial researcher and a community member. Three concepts emerged: *feelings of helplessness*, *role conflict*, and *carrying the burden*. Together, these concepts highlight the challenges associated with balancing differing social roles, and the emotional burden associated with difficult experiences within the data collection process.

### **Feelings of helplessness**

Data collection often took place within participants' home and data collectors were exposed to the realities of living in extreme poverty. Many reported that they felt economic disparities between themselves and the participants, with most describing those experiencing the hardships of poverty as '*suffering*':

*'...the challenges that we have are to see people suffering and telling [us] their problems'***45,WC.**

Some expressed the desire to help participants outside of their role as a data collector; *'I would wish I could take this person to come and stay with me.'***40,WC.**

However, data collectors felt they were unable to act due to a requirement to remain professional. For some, this was challenging. Through the interviews, it was inferred that not acting on a desire to



help, was seemingly different to how they would respond if they had come across such instances in their personal lives; *'...there is nothing else that you can do...you must accept the situation at that moment, you tell yourself that you cannot do anything now because it's about data collection.'* **36,WC.**

This was found to have a negative emotional impact. Feelings of worry, and a desire to further help participants, but being unable to do so personally in the moment, implied concerns regarding role conflict and framed an emerging *feeling of helplessness*.

### **Role conflict**

Despite training around role conflict, many reported developing relationships and supporting participants beyond the requirements of their role, often through giving in-kind. They also described contacting participants in need following data collection or staying with participants longer than necessary. One data collector described how she repeatedly visited and supported a participant following their initial meeting to provide assistance:

*'Oh yes, there is this participant...who told [me] it has been six weeks since their son died and you could see that they were in pain...I told her to call me when she felt she was ready and I would come and check up on her.'* **38,WC.**

For many a feeling of responsibility towards participants emerged resulting in difficulties regarding the maintenance of professional relationships. Participants felt strongly that data collectors should implement change. This feeling was often exacerbated by the difficult circumstances of participants and many reported difficulties striking a balance between being a member of the local community and being an empathetic objective researcher. Yet, most data collectors reported that they were able to maintain confidentiality in their dealings with participants.

*'In the next yard I do what I have to do. Yes, it's going to bother me but I will not discuss with the next house what I saw there... after work you can pick up a phone and find out how she is doing.'* **35,WC.**

### **Carrying the burden**

It was common for data collectors to be emotionally affected by the problems they encountered during data collection. The emotional impact of experiencing participants' disclosure of difficulties was challenging for many. These experiences often led to a sense of concern that infiltrated the data collectors' personal lives and prompted many to evaluate their personal circumstances.

*'...like I mentioned that as a data collector...it becomes hard for me also to stand when they cry, I feel like I should be able to tough and stand those hardships, I tried my best and when you got home you have all those talks you had in your mind...'***28,WC.**

Some reported accessing further support to aid with the emotional impact, seeking formal support through employers i.e. counselling and supervision, and informal support through personal relationships.

## **Breakthroughs**

'Breakthroughs' refers to the positive aspects associated with the experience of data collection. This global theme focuses on the personal development of data collectors and the wider community impact. This section aims to comment on the expected outcomes associated with engaging individuals within data collection but also the positive consequences of data collection within LMIC for both the individual data collector and the wider community.

### **Data collection: A professional stepping stone**

For many, data collection enabled professional growth, skill development and for some altered future career plans. Some commented on their desire to continue within their role and the enjoyment they obtained from their work.

*'If it could be a career Sis... I would pursue it and carry on with it.'***40 WC.**

*'I am on a learning journey at the moment'***38,WC.**

For some, data collection had led them to want to return to education to further train or develop their skill set. For others, gaining employment as a data collector gave them experience necessary to obtain their career goals.

*'To be data collector changed me a lot and I don't see myself doing another thing. I only wish that I could study further.'***36,WC.**

### **Personal growth: Taking lessons home**

In addition to developing professionally, many also developed personally and described the benefits to themselves from undertaking employment as a data collector.

*'I don't want to lie, research has given me more knowledge and changed me to another person.'***35,WC.**

Data collectors who had been involved with the implementation of interventions also developed their knowledge through the acquisition of information from the research project itself. Emphasis was placed on those projects providing parenting interventions, and the application of this information to their personal lives; *'I have learnt that when I speak to a child, not to shout or speak louder, but speak nicely to them because when you shout or beat them they become worse... I must take care of them and give them my love.'***36,WC.**

In addition to knowledge gain, data collectors were often empowered by a growth in confidence and pride in their accomplishments with many gaining skills and knowledge from their work. For some, data collection enabled a sense of awareness and reflection. As one data collector states:

*'I'm very happy that I have grown to understand that life is round and its rotating, you learn until you get old no matter you may think you know everything, you find new things on the field that you had no idea of.'***45,EC.**

### **Developing the community**

Most reported that they felt that research was valued by participants. The undertaking of research within community settings was found to have beneficial effects. The upskilling of data collectors seemingly led to this group becoming key figures within the community and aided their ability to assist their community outside of their role in their day-to-day lives.

*'It has change[d] my way of thinking and made me helpful to others in my community. Now it's easy to solve my problems and others...now I can go outside and give advice to people of my community...'***44,EC.**

Research also acted as a source of support for communities. Many often listened to the concerns of participants outside of the topic of research. For some, this led to participant disclosure and thus the identification of need, allowing for referral to adequate support services: *Sometimes you find out that someone says for example, I was raped [and] I never told anyone and it's the first time I told someone'***38,WC.** In this sense, data collection was viewed as a source of support for communities.

## **Discussion**

This study sought to highlight the experiences of data collectors working within contexts of extreme poverty and violence. This is the first study examining data collector experiences within South Africa using qualitative methods. Thematic analysis identified three global themes of interest namely, barriers, boundaries and breakthroughs. These prominent experiences highlight challenges for data collectors which are seemingly balanced by numerous individual and community benefits. This study feeds into the growing body of literature regarding the impact of research on the research team and on community members involved within the research process. Results confirm and extend the findings of previous research describing risks to personal safety(11,19-23), logistical obstacles (i.e.(20,22), emotional distress(19), role conflict(9,21) and highlight potential implications for the objectivity of data, as well as upskilling and empowerment, both at an individual level(31,37,38) and a community level(39,40).

These data highlight key issues that need to be considered when community data collectors are involved in crucial evidence-based studies. **Barriers** as a theme, highlights the realities of community-based research which bring dangers to the individual inclusive of a lack of safety and wellbeing. As such, training safety protocols and logistical issues should be accounted for within study planning, implementation and evaluation to ensure the safety and wellbeing of data collectors.

The theme of **boundaries** highlights the challenges for data collectors in managing the tension between objectivity and subjectivity within the research process. Many data collectors are drawn to working within their own communities, which brings about a complexity regarding the relationship between being both a researcher and a community member. These data highlight emotional stressors brought about by interactions with community members and as such the potential subjectivity associated with researcher compassion. However, this is paired with an awareness and need to maintain professionalism, distance and scientific objectivity within the data collection process. This contrast placed some data collectors in the situation of a dilemma in the management of their differing roles. This phenomenon invokes an interesting contradiction where, to get representative data, data collectors must build trust and relationships with participants, but an overly established relationship brings about issues regarding role conflict and this in turn may have implications for data integrity. The issue and debate regarding subjectivity and objectivity within research is often focused upon qualitative research.(28) However, these data highlight the topic in the context of both qualitative and quantitative data collection, as this study included participants who had been involved in both. The interview format for quantitative data collection often used within LMIC contexts requires distance and objectivity. Data collectors are however, often exposed to subjective environments which may have an emotional impact and implications for the research process. As such, this interaction between subjectivity and objectivity should be a consideration within the planning and development of research projects. Clarity of referral pathways and boundary setting are important in limiting the personal impact and potential for emotional harm. Previous research has highlighted the benefit of debriefing, teamwork and support pathways as part of good practice standards(41) and such support provision would seemingly be appropriate across both quantitative and qualitative research studies. The emotional anguish experienced by data collectors

should also be highlighted as a risk factor for participants when collecting data(19). Such challenges may be alleviated by being balanced with some of the benefits of being involved within participatory research. These benefits could include involvement in the dissemination process or seeing the widespread implications of research data, i.e.data being used for advocacy in the community or informing policy. Data collector wellbeing remains essential to high-quality research practice and data integrity. Thus, it is important to develop an understanding of the unique role of this group and that their requirements are identified and addressed.

Data collectors cannot be wholly distanced from the research process and any associated data. While the theme of *boundaries*, highlights the potential challenges and considerations brought about by this interaction, *breakthroughs*, highlights the positive implications of data collection and research for both the individual data collector and the wider community. The training and undertaking of data collection itself as well as being exposed to the topic of the research (i.e.parenting) may have implications for personal growth, professionalism and skill building and there is a strong desire for professional and educational development. As such, research may be contributing to the development of transferrable skills that may aid in bridging the skills gap within contexts such as South Africa, where employment opportunities are often limited without tertiary education or a specialised skill. Ostensibly, data collectors are providing a key service in the absence of high-level researchers and are gaining skills that will feed the cycle of information gathering and quality provision. Training and experience is required to increase the robustness of the research process and may catalyse the growth of a professional group that may need to be formalised by experience, certification and standard setting.

The individual experience of the research process may also have a community impact. These results identified data collectors as a source of support within communities, working beyond their role to listen to the needs of the community. Previous studies identified data collectors as gatekeepers within the community(8) or sources of knowledge(42). Thus, formalised training and professional development may have further implications for community development and this should be a consideration within both research and training.

These results need to be viewed in the presence of several potential limitations. Data are country specific; thus, experiences may be specific to the South African context and thus may lack wider generalisability to other LMIC contexts. Nevertheless, research interviews contained a broad range of information regarding data collection experiences across a broad range of settings and contexts, including both urban and rural locations and quantitative and qualitative data collection. The data are also gender specific which may restrict generalisability of findings. However, it should be noted that a higher number of females were identified as eligible for the wider research study and, based on anecdotal evidence, data collection is often a role predominantly undertaken by females within LMIC.

Data collectors provide a fundamental service and help bridge a crucial gap in capacity within the field of health research. Their contribution to the research process should therefore not be overlooked. Considerations of their needs and realities are required within research planning and implementation to ensure adequate support, standardisation and data quality. This study has highlighted some of the experiences of data collectors, exposing both challenges and opportunities for this group and considerations regarding the research process. The increasing use of data collectors within health research necessitates a greater understanding of the impact of such experiences on the wellbeing of individuals, the wider community and on the wider research context. An improved understanding of such phenomena is vital to inform the planning and practice of future research endeavours, develop training and support provisions, and to aid in the formulation of standardised practice within such environments.

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