Reflexivity and the challenges of collecting sensitive data in India: a research note
Judith Fletcher-Brown
University of Portsmouth, UK

Corresponding author:

Judith Fletcher-Brown, Portsmouth Business School, University of Portsmouth, Burnaby Terrace, Burnaby Road, Portsmouth, Hampshire PO13AE, UK. Email: judith.fletcher-brown@port.ac.uk

Abstract

As health advertising researchers we become involved with a variety of health and well-being issues in order to advance social marketing research. Health advertising research involves mainly face-to-face encounters with participants using qualitative methodologies. This article explores the challenges a researcher of British origin faced undertaking fieldwork in India in an effort to collect qualitative data about breast cancer awareness (BCA) and prevention, a culturally taboo subject. Key obstacles included cultural barriers, research method assumptions and researcher resilience. Reflexivity has been recognized as a crucial stage in the process of generating knowledge via qualitative research processes. Thereby applying the critical lens of reflexivity, this article reflects upon the complexities of accessing Indian women (a fiercely private demographic) to participate in discussions about the sensitive topic of breast cancer. The results are discussed and recommendations from this researcher's experience are presented as a resource to assist future qualitative health advertising inquiry

Keywords

culture, email questionnaires, health advertising, India, reflexivity, sensitive data

Introduction

The context of this article is health advertising research, which lies within the academic sphere of social marketing (Friedman et al., 2016; George et al., 2016; Wymer, 2011). The majority of health advertising investigations support the assumption that face-to-face encounters with participants is a superior qualitative methodology to gather rich insightful data on sensitive health issues (Dickson-Swift, 2017; Jacobsson, 2016; Holt, 2010; Poudel et al., 2016). In this study this innocent notion of participation was seriously tested. The findings contribute to the growing recognition that undertaking qualitative health research can pose additional challenges to data collection. In particular the recruitment of respondents where the subject to be discussed is sometimes a cultural or gender sensitive topic (Agbemenu et al., 2016; Chan and Shaw, 2016; Koziol-McLain et al., 2016; Padgett, 2016; Rahill et al., 2016).

Reflexivity has raced to the forefront of qualitative research because of the unique position of the neutral objective researcher (Kumsa et al., 2015). There is a considerable body of literature on reflexivity in the development of management literature, whereby the demands for reflexive writing are discussed because of the benefit it provides to researchers (Van Maanen, 2006; Mahadevan, 2011). An example is the work of Van Maanen (1988) who

called for researchers to reflect upon the effects the research context and their interrelation in the field influence them or not. In particular, how these issues and experiences impact on them making conscious plausible choices in writing up their study. Field experiments demand the researcher's bodily presence enabling them to experience and gain first hand in sight into the phenomena to be examined, therefore, researchers need to reflect upon themselves and their interrelations in the field (Van Maanen, 1988; Geertz, 1973).

But this is not an easy or simple methodological process and has been labeled 'messy' (Kumsa et al., 2015: 420). For example, if the researcher has experienced the same phenomena herself 'this allows her to gain additional insights into the field though reflexivity beyond introspection' (Mahadevan, 2015: 380). Therefore, the researcher may find themselves in a state of 'embodied knowing' that is pre-reflexive and messy (Mahadevan, 2015: 380). However, this notion of pre-reflexivity has received recent support from Ellingson (2017: 83) who urges qualitative researchers 'to resist the mind–body split [sic] and embrace their search for knowledge production as deeply embedded in sensory experience.' Therefore, reflexivity is present at every stage of the investigation, including the motive behind the questions asked through to the composition of the final writing.

Prior to commencing the project, I consulted the reflexivity literature pertaining to field study in a different geographical location. Mahadevan (2015: 367) discusses 'embodied ethnography' and the importance of 'fitting in and not violating cultural norms', because 'not getting it quite right' will impede data collection (2015: 362). For example, I dressed appropriately for the conference and researched cultural business practices in India. This additional effort is critical if the field researcher does not wish to be perceived as 'the elephant in the room' (Bell and King, 2010: 30). Satisfying costume requirements is fairly easy to meet, the difficulty for this researcher was reflecting upon the overwhelming experience of field work in India as previously highlighted in Van Maanen's (1988) study. However, the literature says in order to make the problem less challenging and more manageable begin with the reflexivity process with one phenomenon experienced by the researcher which may prove helpful to other qualitative researchers. Then the next phenomenon and so forth. Therefore, I believed my embodied knowing of surviving breast cancer would encourage a deeper level of insight from those questioned, perhaps by experiencing similar thoughts and feelings that were prevalent throughout diagnosis and treatment.

In this article, I intend to reflect upon the complexities of accessing a fiercely private demographic (such as Indian women), to participate in discussions about a sensitive health topic (BCA). My argument is derived from my own experience as a female white British national, conducting field research in India and who is a breast cancer survivor. In doing so, this research note attempts to take up the call for reflexivity work which could be used as a resource for others actioning similar qualitative health inquiry who may or may not have experience of the phenomenon to be investigated (Brockmann, 2011; Hammersley, 2017; Hate et al., 2015; Holloway and Galvin, 2016; Jack, 2016).

Berger (2015: 199), discusses the benefits and challenges to reflexivity within three different researcher positions including 'shared experience, insider position and the researcher without personal familiarity of the subject.' The outcomes of this research illustrate first, that a researcher's shared experience of the subject does not guarantee a positive effect on the data gathering experience. A researcher's demography such as race and nationality have greater resonance with the respondent than any personal familiarity with the

research issue to encourage engagement. Second, be wary of innocent notions that participation by respondents is a guarantee because in this research an inequitable power relationship existed between myself and the women. Their position was one of power over the investigator which manifested from the cultural protocol that existed in India. This unbalanced relationship forced me to review the methodology I assumed would be appropriate. Lastly the researcher's own experience and subjective knowledge of the disease manifested in a dogged resilience to overcome cultural challenges in an effort to pursue the women, demonstrating the need for researcher resilience.

Research study context

In India, breast cancer is the most commonly diagnosed type of cancer for urban Indian women and will be the most common type of cancer among all women in India by 2020 (Bawa, 2012; Murthy et al., 2007; Shetty, 2012). Studies show women seek medical care extremely late due to a lack of awareness about self-examination and India's unique socio-cultural complexity (Rath and Gandhi, 2014; Shetty, 2012). The health advertising literature suggests that a coherent targeted health advertising campaign would produce increased awareness to women in India, therefore to inform any future BCA campaigns, it was important to seek and engage their opinion in their locale (Bawa, 2012; Murthy et al., 2007; Shetty, 2012). The planning and execution of the data process was over a very lengthy period (12 months) including initiating contact with gatekeepers, building relationships on trust and finally collecting the data from the participants (Bahn and Weatherill, 2013; Maguire et al., 2015; Namageyo-Funa et al., 2014). Although a simultaneous pursuit of a separate group of participants (medical experts in cancer care) was also under taken, this research note identifies the challenges faced engaging Indian women to participate in face-to-face discussions (Dempsey et. al., 2016).

Method

The study adopted an interpretative-inductive exploratory methodology which enabled information to be revealed about this sensitive area where knowledge is currently sparse (Aziato et al., 2016; Verhaeghe and Vandecasteele, 2016). When I commenced this research I did not question the assumption that the most appropriate method for collecting data from the medical professionals would be via focus group and face-to-face interviews with Indian women. Such assumptions are appropriate in social science research (Irvine et al., 2013). Following the guidance of Hammersley and Atkinson (2007) the questioning of both groups of participants would encourage exploration about their knowledge, thoughts and experiences concerned with BCA. For example, the Indian women participants could recount personal experiences and those of family members and friends, however, this demographic proved difficult to access as interviewees. The challenges of managing unexpected changes in data collection methods (than those originally planned) has provided me with knowledge and experience to share with other qualitative health researchers.

The methodology was as follows: Stage 1 – a pilot study consisting of a semi-structured focus group with medical cancer experts to obtain multiple opinions on the subject. It consisted of a heterogeneous range of cultural groups from India with a homogeneous sample of men and women (Krueger and Casey, 2014; Galesic et al., 2015; Mackey and Bassendowski, 2017; Meyer and Peng, 2015; Zikmund et al., 2014). Stage 2 – semi-structured interviews with Indian women. These were to be conducted in English, audio-recorded (with their permission in line with the University Ethics Committee) and facilitated

by a protocol guide to facilitate the topic of interest and avoid loss of direction. Hence, it was anticipated that the questions would be mostly open-ended and discovery-oriented to facilitate open discussion and enquiry (Yin, 2014).

However, the semi-structured interviews proved to be exceedingly challenging. What follows is a reflective review about the challenges of accessing women to develop a discussion and collect sensitive data in order to complete the methodology as planned (Hall, 1997; Krippendorff, 2004; Remenyi and Williams, 1998). The findings from the data collection uses thematic analysis and the participant's words are quoted verbatim to enhance validity (Braun et al., 2014; Denzin and Lincoln, 2000; Kreutzer et al., 2017; Hsieh and Shannon, 2005). These emerging themes are categorized and reported in three parts, cultural barriers, research method and researcher resilience.

The research process

In any investigation about the experience of undertaking sensitive health research, it is important to first consider what it is that we, as qualitative researchers, actually do. We arrive in people's lives often at a time of misery and distress and ask them to divulge intimate thoughts and feelings about their experiences (Dickson-Swift, 2017). Procedures for managing discomfort and distress of the participant should be included in the Participant Information Form (PIF) which should be signed as part of the university ethics procedure. My experience shows consideration of the participant's needs at interview, is paramount otherwise it is doubtful the dyadic process will have positive outcomes for either party.

During the planning stages finalizing contact with key medical experts in cancer care was seamless. Almost immediately after the initial email contact, two oncology hospitals agreed to participate and focus groups were arranged. Confirmation of a favorable review from the University Ethics Committee to undertake the research, was sufficient authentication for the hospitals to commit to take part. This was contrary to my assumption that medical professionals would be reluctant to participate. Interviews for Stage 2 were arranged to be held at a professional conference in India. An invitation to take part was sent to the delegates via the conference organiser. Those who agreed to be interviewed signed a PIF and returned this to the gatekeeper. I travelled to India to implement both stages of the research. Stage 1 was executed successfully. On arrival at the designated interview room where the interviews were to be conducted (Stage 2 of the data collection), to my disbelief none of the participants attended. Although I had all the checks and balances in place about ethical clearance for both stages of the data collection the demographic proving most difficult to reach were Indian women and not the medical professionals. I left India without their contribution.

This incident highlighted the little control I had in reality over collecting data in this culturally complex country. Even though the participants were educated, professional working women it was apparent their gender marginalised them in India society and impacted on their decision to be interviewed. They explained their non-attendance to me in an email: 'I feel worried about cancer . . . but I would feel afraid about talking in a meeting' and 'As the interview time approached I felt very nervous about talking to you about breast cancer . . . it is not discussed' and 'I felt very shy about discussing the subject with someone I didn't know.'

This experience corroborates the work of Fawcett and Hearn (2004), who reflected researchers studying a familiar subject still lack immediate points of cultural identification

because an absence of direct experience. Therefore, studying an unfamiliar group made me acknowledge my own insight of the subject and my national identity could both help and hinder the research process (Berger and Rosenberg, 2008). For example, personal knowledge of breast cancer was useful in formulating and conceptualizing research questions relevant to the participant's experience. However, my demographic disposition did not initially encourage discourse. The plurality of the situation was evident. Cultural protocol did not empower the women to enter into discussion about the sensitive research topic. Their power existed in their control over me, the researcher, who was consequently disempowered and without influence.

However, from a methodological perspective it was important to re-establish a connection with the same women because they were living and working in the same locale as the participants in Stage 1 of the data collection process. The common geographical locale would help me to achieve a 'naturalism' of participants and a generalisability of the findings (Paluck, and Cialdini, 2014: 82). The women had freely given me their business cards at the professional conference and so contact was re-established after a time consuming series of negotiations using email. Many of the same women agreed to continue to participate in my study, but not on a face-to-face basis. In consideration of their comfort and the sensitivity of the issue, I encouraged participation via email which overcame their reserved nature and their concerns about meeting me face- to-face. The participants were able to use the email method of communication to conquer any concerns of confidential disclosure about the sensitive nature of the discussion topic and maintain their privacy. One woman said 'I did not want to talk about private matters . . . embarrassed about talking' but did participate via email.

This technology proved an appropriate data collection method. They were able to respond to the contents of the email at their convenience and because of their location in India, it was a practical option. My experience corroborates the literature which suggests this computer-mediated method enables a researcher to engage in dialogue with isolated, geographically dispersed or marginalized groups (Gibson, 2010; Mann and Stewart, 2000). I found this electronic interviewing method created a free exchange of information without any pressure for the participant to conform and most importantly without my presence (Zikmund et al., 2014).

Reflexivity literature identifies familiarity with the subject as a risk because often there can be a blurring of boundaries where the researcher imposes their own values and beliefs on to the project (Drake, 2010). In particular this is more apparent with face- to- face interviews where a continuum between the participant and the researcher exists as one interprets the other's dialogue and assumes there is a common understanding about their point of view and experience (Berger, 2015). However, the email method of data collection did in effect maintain a separation of this continuum (the respondent's experiences and my own) because the communication was always in one direction, without the other interjecting, insinuating or leading the other to make assumptions.

Furthermore, I gained insight into their own cultural frames of reference about participating in face-to-face interviews which I found to be anchored in India's complex social influences (Greenwood et al., 2014; Patton, 2002; Usher-Smith et al., 2016). Participants explained 'My husband was not cooperative in enabling me to participate in the interview' and 'I would prefer not to meet you because I am shy talking about such matters and my husband would be angry.' Others said 'I felt very shy about discussing the subject with someone I didn't know.' Their reasons for not participating were similar to those which

prevent women accessing breast cancer health services such as family obligations and generally being over-dependent on other family members to make decisions (Deshpande et al., 2013; Murthy, 1982). For example, 'I agreed to be interviewed but was worried about my family's reaction.' Although I was fully aware that asking questions about the female body should be handled with sensitivity, I was not mindful of the protocol that existed between husband and wife, daughter and father in India. Even though these women were educated and possessed a degree of economic independence, they still needed permission to engage with me.

A critical reflection from this project recommends to other qualitative researchers not to be guided by their assumptions about the research context, nor be too rigid with their methods. For example, this researchers experience would recommend a degree of flexibility to the proposed collection method in consideration of the cultural context and the nature of the participant group. The adaptability and resilience of the researcher to challenging situations within the research data collection process is fundamental to successful outcomes.

Conclusions and recommendations

This article focused on the challenges experienced by the health researcher whilst collecting sensitive qualitative data in a different cultural geographical location, India. A contribution to knowledge is made by illustrating the reflexivity process is beneficial for future researchers, but challenges Berger's (2015) proposition that shared experience of the subject is a positive influence on data gathering .Through the lens of reflexivity the outcomes of the investigation illustrate that a researcher's shared experience of the subject does not soften the challenge nor guarantee a positive effect on the data gathering experience. Indeed, this researcher's social position (in particular race and nationality) was a considerable factor (in encouraging the women to take part) over and above any empathetic emotional bond felt by the respondent for the investigator's personal familiarity with the subject. This consequence from the investigation supports Hibbert et al. (2010) who acknowledge the limitations of the reflexive process and posit reflexivity should only be used to convey cultural meaning to the reader or to gain deeper insight into the field of research otherwise there is a risk of messy methodological processes (Kumsa et al., 2015).

Contrary to common assumptions about data collection methods, this article has identified conducting semi-structured interviews via email is not a second best option to face-to-face interviewing. Indeed, in an emerging economy it proved a sound methodological and practical method. I recommend to other health researchers when planning data collection, not to be guided by their assumptions, to factor in a contingency plan and to prepare to be resilient throughout the months of planning and execution of data collection.

The findings from this study demonstrate that health advertising researchers do experience a number of challenges throughout the data collection process including, the length of the research process, travelling long distances, managing the sensitivity of the health issue and preserving anonymity of the participants. My experience appends the problem of engaging female participants to take part in-depth interviews on sensitive topics, to that list. Altogether these challenges have a very real impact on the resilience of the researcher often ending in frustration and exhaustion. Campbell (2002) and Johnson and Clarke (2003) identified the research process impacts greatly on the mental and physical exhaustion of the researcher and my experience of recent data collection in India corroborates their findings and concludes researcher resilience is still a key characteristic demanded today.

There are many formal and informal channels of support for researchers provided at university, professional development and subject specialist level, however, the benefit of genuine researcher experience is a very powerful resource (Ellington et al., 2013; Smith et al., 2013). Therefore, I would suggest before embarking upon a health research study on a sensitive topic in another cultural locale, the individual should be prepared for challenges that may impede the smooth process of research. Significantly do not make assumptions about methods of data collection, because the researcher may need to react quickly and utilise another method if participants do not conform as expected.

The external validity of these results would benefit from further empirical field research. In particular, with health researchers from a range of national backgrounds undertaking field research in different cultural settings. In time their own findings would extend the three outcomes about reflexivity discussed here which would enable the formulation of a comprehensive set of guidelines that would be applicable across all fields of qualitative health research.

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Author biography

Judith Fletcher-Brown is a Senior Lecturer in Marketing at the University of Portsmouth. Her research interest is health intervention campaigns with gender focus and an international cultural perspective. She has produced a series of papers examining Human Papillomavirus vaccine campaigns in the Philippines disseminated at a variety of conferences including European Social Marketing Conference and British Academy of Management. Her current focus is examining mobile technology health solutions to breast cancer awareness in India. Her latest article (with Pereira and Nyadzayo) was published in 2018 in the *Journal of Business Research*.